Perceptions of Health Care:

Perspectives from Adolescents with Physical Disabilities and their Parents

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A thesis submitted to the School of Graduate Studies

In partial fulfillment of the requirements for the degree of

Master of Science

Department of Psychology

Memorial University of Newfoundland

October 2015

St. John's

Newfoundland and Labrador

Abstract

Patient satisfaction with health care is an important indicator of quality services and has been related to positive health outcomes. Because little is known about whether adolescents with physical disabilities are satisfied with the services they receive, the current study investigated the extent to which adolescents are satisfied with health care services, aspects of care adolescents identify as important to their satisfaction, similarities between adolescent and parent perceptions of care, and the relationship between adolescent perceptions of care and their intentions to adhere to treatment recommendations. Following recruitment from a pediatric health center, adolescents and their parents (n = 42) completed questionnaires to assess their perceptions regarding various aspects of health care services. Participants were very satisfied with services received; interpersonal aspects of care were very important to them. Adolescents' satisfaction was not predictive of their intentions to adhere to treatment recommendations and their perspectives differed from those of their parents.

Acknowledgements

Foremost, I would like to express my sincere gratitude to my supervisor, Dr. Christine Arlett. Thank you for your continuous support, immeasurable patience, immense knowledge, and inestimable guidance during my study and research. I could not have imagined having a better supervisor and mentor. Thank you for all you have done to help me to complete this project. Words do not sufficiently convey the deepest appreciation and utmost respect I have for you. Thank you.

Secondly, I would like to thank my thesis committee, Dr. Cathryn Button and Dr. Janine Hubbard. Thank you for your encouragement, insightful comments, and thoughtful questions. I truly appreciate you giving your time and your knowledge to this project.

Thirdly, I would like to thank the Department of Psychology, the School of Graduate Studies, and the Newfoundland and Labrador Centre for Applied Health Research for your financial support during my research. It would not have been possible to complete this project without your contributions.

Finally, I would like to thank the adolescents, parents, and health care professionals who participated in this research. Thank you for your enthusiasm, your time, and your valued opinions.

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INTRODUCTION

Patient satisfaction with health care is an important indicator of quality of health services (Donabedian, 1992). Health care providers now assess patients' perceptions of health care more frequently, particularly regarding the degree to which patients are satisfied with the care provided (Sen et al., 2005). Satisfaction with health care is important because it is associated with positive health-related patient behaviors including choosing to seek treatment (Zastowny, Roghmann, & Cafferata, 1989), maintaining a relationship with a medical practitioner (Riley, Stromberg, & Clark, 2005), attending follow-up appointments (Freed, Ellen, Irwin, & Millstein, 1998), and adhering to treatment regimens (Hirsh et al., 2005; Martinez et al., 2012). Patient satisfaction with care is thus related to overall improved health outcomes (Sen et al., 2005; Squier, 1990).

Researchers have investigated the extent to which adult patients are satisfied with the health care services they receive for both acute and chronic conditions; factors that are predictive of their satisfaction have also been identified (e.g., Hirsh et al., 2005). Similarly, the perspectives of parents with children receiving health care services for acute and chronic conditions have been studied and factors important to their satisfaction have been identified (e.g., Knapp, Madden, & Marcu, 2010; Law et al., 2003).

Few studies exist, however, that have sought the perspectives of children and adolescents regarding their perceptions of the health care they receive. Even fewer studies have sought the perspectives of adolescents with chronic health conditions and disabilities. It has been common practice to investigate the perspectives of adolescents' parents regarding their satisfaction with health care, rather than asking adolescents themselves directly about their experiences and opinions (Garth & Aroni, 2003).

However, parental perspectives may not be accurate representations of adolescents' perspectives (Byczkowski, Kollar, & Britto, 2010; Mah, Tough, Fung, Douglas-England, & Verhoef, 2006). The opinions of adolescents regarding their health care have for the most part been unheard, both in the medical encounter (Burstein, Bryan, Chao, Berger, & Hirsch, 2005; van Dulmen, 1998) and in the research community.

Adolescents with chronic health conditions and disabilities are chronic and frequent users of the health care system (Newacheck & Kim, 2005; Newacheck & Taylor, 1992); they avail of more health care services and use these services more frequently than their healthy counterparts (Szilagyi et al., 2003; U.S. Department of Health and Human Services, 2007). Despite their high level of health care utilization, little is known about whether adolescents with chronic conditions are satisfied with the services they receive, nor have factors important to their satisfaction been identified; even less is known about the perceptions of adolescents with physical disabilities.

The current study investigated four questions concerning the perceptions of adolescents with chronic physical disabilities regarding their health care:

(1) To what extent are the adolescents satisfied with the health care they receive?

(2) Which aspects of care do the adolescents identify as important to their satisfaction?

(3) How similar are adolescent perceptions of care to those of their parents?

(4) Do adolescent perceptions of care relate to their intentions to adhere to treatment plans?

The following literature review will begin by exploring the definition, characteristics, prevalence, and health care utilization of adolescents with chronic health conditions, including physical disabilities where possible. The definition of satisfaction, its importance to health care, and factors predictive of satisfaction in adult, parent, and adolescent patients will then be discussed. Finally, the importance of treatment adherence, its relation to satisfaction, and barriers to adhering to treatment will be reviewed.

Although adolescents are of interest in this study, not all previous studies have made the distinction between age groups included in their sample. For example, some studies have used the term children to refer to all individuals younger than age 18 years, while other studies have distinguished children from young adolescents and older adolescents. Therefore, for simplicity, the term children will be used to refer to both children and adolescents younger than 18 years of age throughout the remainder of this discussion.

What is a chronic health condition or a disability?

Children with chronic health conditions and disabilities in Canada are primarily identified using the definitions outlined by the World Health Organization (WHO), summarized in McDougall et al. (2004). *Health conditions* refers to diagnosable diseases and disorders, injuries, and related health problems; health conditions that are permanent or persist for longer than three months are considered *chronic conditions*. *Disability* refers to impairments, activity limitations, and participation restrictions; it reflects the interaction between an individual's body and the environment in which they live (World

Health Organization, Health Topics: Disability, n.d.). *Impairments* refers to a loss or abnormality at the level of the body, body part, or organ; *activity limitations* involve difficulties an individual may have in executing a task or action; and *participation restrictions* refers to difficulties with involvement in education, social life, or other life situations (World Health Organization, Health Topics: Disability, n.d.).

In the United States, multiple definitions have been used to identify children with chronic health conditions and disabilities including the presence of specific diagnoses (such as cancer or diabetes), impairment in basic functions (seeing or hearing), impairment in higher levels of functioning, and limited ability to conduct activities of daily living (Newacheck et al., 1998; Szilagyi et al., 2003). These definitions were criticized as being too narrow, omitting children who function well but require special services and equipment to maintain function (McPherson et al., 1998) and excessively limiting the number of children eligible for funding programs and special services (Newacheck et al., 1998). Discrepancies in the definitions used across individual studies led to wide variation in estimates of prevalence, epidemiology, and outcomes of children with chronic conditions and disabilities (Merrick, 2000; Newacheck & Taylor, 1992).

In response, the United States' federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs developed a new, universal definition of children with special health care needs:

> Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a

> type or amount beyond that required by children generally (McPherson et al., 1998).

This definition is very inclusive. It not only includes children with existing chronic conditions and disabilities, but includes children at heightened probability of developing chronic conditions due to biological or environmental risk factors; examples of children at risk include those experiencing extreme poverty, abuse or neglect, second-hand smoke, very low birth weight, metabolic deficiencies, or chromosomal abnormalities (McPherson et al., 1998). In the United States, this definition of children with special health care needs is used in federal health care policies (McPherson et al., 1998) and in the more recent research literature (e.g., Bethell, Read, Blumberg, & Newacheck, 2008; Newacheck, McManus, Fox, Hung, & Halfon, 2000; Szilagyi et al., 2003).

Considerable research has been conducted using the above definition of children with special health care needs to estimate the prevalence, characteristics, outcomes, and health care utilization of these children in the United States; further reference to American studies on this topic will refer to this definition unless otherwise indicated. Little is known, however, about the characteristics of children with chronic health conditions and disabilities in Canada; because different definitions have been used across studies, it is difficult to clearly understand the prevalence and epidemiology of childhood chronic conditions and disabilities in Canadian samples (McDougall et al., 2004). Therefore, the following review will refer to Canadian literature where able, and American literature where necessary, recognizing that differences in definitions,

populations, methodologies, and health services renders direct comparisons of Canadian and American findings impossible.

What are the common conditions?

While children with special health care needs represent a variety of chronic diseases and impairments, the most commonly reported conditions in Canadian children were allergies, asthma, and bronchitis (McDougall et al., 2004). Respiratory diseases, especially asthma, and impairments of speech, special sense (e.g., vision, hearing), or intelligence were the most commonly identified chronic conditions affecting children in the United States; each of these accounted for more than 25% of all identified cases of childhood disability (Newacheck & Halfon, 1998). Physical disabilities such as cerebral palsy and spina bifida are less common (Wallander, Feldman & Varni, 1989). For example, less than 1% of children in Manitoba were diagnosed with physical disabilities including spina bifida, cerebral palsy, and other paralytic conditions (Kozyrskyj & Hildes-Ripstein, 2002). Although they occur infrequently, cerebral palsy and spina bifida are important to consider when discussing chronic health conditions because they are the two medical conditions involving central nervous system lesion that most often result in physical disability (Wallander, Feldman, et al., 1989).

Cerebral palsy describes a group of permanent disorders of movement that result in activity limitation. The disorders are attributed to non-progressive disturbances in the fetal or infant brain (Smith, Kelly, Prkachin, & Voaklander, 2008; Weigerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006) and it is a clinical descriptor rather than an etiologic diagnosis (Rosenbaum, Livingston, Palisano, Galuppi & Russell,

2007). The motor difficulties associated with cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour (Rosenbaum et al., 2007). Cerebral palsy is associated with muscle weakness, spasticity, and incoordination which can make daily activities, such as walking and dressing, difficult for children diagnosed with the disorder (Shields, Loy, Murdoch, Taylor, & Dodd, 2007). Cerebral palsy is considered to be the most common, most disabling chronic childhood disorder, although it affects only two to three per 1000 live births (Smith et al., 2008).

Spina bifida has been defined as a spinal deformity caused by the incomplete closure of one or more vertebrae (Wallander, Feldman, et al., 1989). It is a neurological disorder that includes multiple complex congenital abnormalities and anomalies involving the imperfect development of the neural tube and related structures (Kaufman, 2004). Bodily structures that may be affected include the spinal cord, brain, bony spine, extremities, bowel, and bladder (Kaufman, 2004). Secondary conditions resulting from spina bifida may include infections of the central nervous system, hydrocephalus, neurogenic incontinence, and lower extremity paralysis (Wallander, Varni, et al., 1989). Spina bifida has been identified as the most frequently occurring central nervous system malformation, and the second most common specific birth defect (Wallander, Feldman, et al., 1989). It affects approximately one in 1000 live births, but the overall incidence has been declining since 1980 (Kaufman, 2004).

As noted above, physical disabilities occur in a very small proportion of children and very few research studies have investigated the outcomes and health care utilization of these children specifically. Due to the paucity of research regarding children with

physical disabilities, the remainder of this discussion will address the prevalence, characteristics, outcomes, and health care utilization of children with special health care needs, of which children with physical disabilities are a part. Explicit and specific reference to children with physical disabilities will be made where research findings make it possible.

What is the prevalence of children with special health care needs?

Merrick (2000) investigated the prevalence of adolescents with mental and physical disabilities from 1946 to 1998 based on studies from the United Kingdom, the United States, Scandinavia, and Israel. Disability was defined as any restriction or lack of ability to perform a task or activity in the manner or within the range considered normal for the age and for a duration of more than three months. Chronic illness was defined as a physical, usually non-fatal condition that lasted longer than three months in a given year or necessitated a period of continuous hospitalization of more than one month.

Merrick (2000) reported that the percentage of children diagnosed with a disability varied between 7.7% and 18% depending on the geographical area and time frame studied. Specifically, from 1946 to 1961 in the U.K., 11% of children younger than age 16 years had been diagnosed with a disability. In the United States in 1971, 11.8% of children younger than 18 years of age had been diagnosed with a disability including respiratory, neurological, sensory, musculoskeletal, and other conditions; this figure rose to 18% in 1994. There had been 7.9% of Scandinavian children aged 2-18 years diagnosed with a disability in 1984-85, and 7.7% of children in Israel during 1995-98. The author attributed the differences in prevalence of disability among children to

differences in the definitions used, the populations sampled, societal attitudes toward disability, and medical and technological advances improving survival rates over time (Merrick, 2000).

Using the definitions provided by the WHO, McDougall et al. (2004) conducted a study to investigate the prevalence of children with chronic health conditions and disabilities in Canada. The researchers used information from 1994-1995 National Longitudinal Survey of Children and Youth (NLSCY) pertaining to the sample of children ranging in age from six years to eleven years. They found that 30.3% of these children were reported to have one or more chronic physical health condition or impairment including allergies, asthma, heart disease, bronchitis, kidney disease, epilepsy, and other conditions. The authors also found that 11.5% of children with chronic conditions and 23.1% of children with impairments were reported to have activity limitations as a result of their condition. The definition used as inclusion criteria for this group of children is similar to the definition used by the American studies discussed below.

Several studies have investigated the prevalence of children with special health care needs in the general population in the United States based on the National Health Interview Survey, which is administered regularly to assess the health status and the use of health services by the US civilian population. In 1994, a specialized survey was added assessing the prevalence and health services use of people with disabilities. Using information from this survey, Newacheck et al. (1998) found that 12% of American children under the age of eighteen years had a chronic physical, emotional, developmental, or behavioral condition using the categorical definitions in place in 1994,

and 18% of children in the US had a special health care need using the more recent definition.

The first large scale study to specifically assess the health and health care experiences of this population of children was the National Survey of Children with Special Health Care Needs in 2001 (Kogan, Strickland, & Newacheck, 2009). Participants were selected using a random-digit-dial telephone method and interviewed using a health care screening tool (Children with Special Health Care Needs Screener). Van Dyck, Kogan, McPherson, Weissman, and Newacheck (2004) used data from this survey to determine the prevalence of children with special health care needs. The authors found that 12.8% of children in the United States younger than eighteen years of age were identified as having a medical, behavioral, or other health condition that had or was expected to last twelve months or longer and that had resulted in functional limitations, elevated needs for medical care, mental health, or education services or needs for specialized therapy or prescription medications. This study's methodology was repeated during the second national study in 2005-2006 (Kogan et al., 2009). Investigators found that 13.9% of children in the United States were identified as experiencing a special health care need, with 1.9% of this population reporting a diagnosis of cerebral palsy (U.S. Department of Health and Human Services, 2007).

Bethell et al. (2008) used data from multiple American national surveys to investigate variations in the prevalence of children with special health care needs over time. The authors compared survey data regarding children with special health care needs from the 2001 National Survey of Children with Special Health Care Needs, the 2003 National Survey of Children's Health, and the 2001-2004 Medical Expenditure

Panel Surveys; each of these surveys used the same screening tool to identify children with special health care needs but used different sampling strategies. Bethell et al. (2008) determined that 12-20% of American children aged 0-17 years experienced a special health care need, and that this prevalence range remained consistent across time. The authors concluded that prevalence is better expressed as a range to account for variations in survey methodologies.

In summary, the prevalence of children with special health care needs ranges from 7.7% to 30%, depending on the country studied, the year(s) sampled, the ages of children included, and the definition of disability used. Other factors contributing to the discrepancy in prevalence estimates across countries and time include (1) increased access to diagnostic services, (2) societal attitudes toward disability, (3) better recognition of children's conditions on the part of parents and physicians, (4) medical and technological advances improving survival rates over time, and (5) a true increase or decrease in the prevalence of chronic conditions in the population (Merrick, 2000; U.S. Department of Health and Human Services, 2007).

Who is affected?

Newacheck et al. (1998) and McDougall et al. (2004) reported on the demographic characteristics of children with special health care needs in the United States and in Canada, respectively. They both indicated that boys were more likely than girls to have a special health care need, and chronic health conditions and disabilities were more prevalent among children from families with incomes below the poverty level and among children from single-parent families. Van Dyck et al. (2004) reported similar

findings, but also identified demographic characteristics of age and race as predictors of special health care needs. Older children were more likely than younger children to have a special health care need, and non-Hispanic white and black children were more likely than Hispanic children to have experienced a special health care need (van Dyck et al., 2004).

How are they affected?

Children with chronic health conditions and disabilities experience disruptions in daily functioning due to their condition. 11.5% of Canadian children with chronic health conditions and 23.1% of Canadian children with disabling impairments were found to be limited in their ability to perform daily activities, and 24.7% of children classified as having 'other conditions' (including cerebral palsy) were reported to be limited in their ability to participate in activities at school, at play, or during other age-appropriate activities due to their condition (McDougall et al., 2004).

American national studies have included questions concerning the extent to which children's condition(s) impacted on their ability to participate in activities typical of their peers and on their ability to perform their normal daily activities. Regarding their participation in activities typical of their peers, findings from the 2005-2006 National Study of Children with Special Health Care Needs indicated that 39% of children with special health care needs were 'moderately' affected some of the time by their condition, and 24% of children with special health care needs were 'usually' or 'always' affected a great deal by their condition (U.S. Department of Health and Human Services, 2007). On average, children in the United States with special health care needs were restricted in

performing activities they could normally perform for approximately two weeks each year due to their condition (Newacheck & Halfon, 1998).

Children with special health care needs were found to spend on average three times more days ill in bed and two to three times more days absent from school than other children (McDougall et al., 2004; Newacheck et al., 1998). Children with special health care needs missed an average of seven days of school a year, and 27% of children with special health care needs missed seven or more days of school annually (U.S. Department of Health and Human Services, 2007). In fact, 23% of American children with special health care needs were unable to attend school or were limited in their ability to attend school on a regular basis because of their condition (Newacheck & Halfon, 1998).

Children with physical disabilities were also affected by their condition in terms of daily functioning. For example, Newacheck and Taylor (1992) reported that 89% of children with cerebral palsy in the United States were limited in their ability to conduct usual activities; they spent an average of 1.7 days in bed and missed an average of 2.3 days of school annually due to their condition.

In addition to disruptions in daily functioning, chronic health conditions and disabilities have also been found to impact on children's social functioning. According to studies using the Child Behavior Checklist (a measure of behavioral and social functioning), children with physical disabilities were reported to have lower social competence scores than normative samples (Pinquart & Teubert, 2012; Wallander, Varni, Babani, Tweedle Banis, & Thompson Wilcox, 1988; Wallander, Feldman, et al., 1989; Wallander, Varni, et al., 1989). They were reported to be less involved in social

activities, hobbies, and daily chores than normative samples (Pinquart & Teubert, 2012; Wallander et al., 1988) and they indicated that it was difficult for them to make and communicate with friends or to spend time with friends outside of school (Stevens et al., 1996).

Similarly, adolescents with cerebral palsy reported that they were less exposed to their peers' culture, spent less time with friends outside of school, dated at a later age, dated less frequently, and had lower levels of sexual knowledge and experience than their non-disabled peers (Wiegerink et al., 2006). The researchers suggested that the lower social competence and decreased social involvement may have resulted from physical and cognitive limitations, mobility difficulties, dependence on parents, and a lack of transportation to social activities (Pinquart & Teubert, 2012; Stevens et al., 1996; Wallander et al., 1988; Wallander, Varni, et al., 1989; Wiegerink et al., 2006).

How much do they use the health care system?

Children with special health care needs are often in poorer health than other children (Szilagyi et al., 2003) so it stands to reason that they use more health care services than other children. On average, children in the United States with special health care needs had contact with a physician between 9 and 16 times a year and accounted for 19% of all physician contacts (Newacheck & Halfon, 1998; Newacheck & Taylor, 1992). This group of children spent eight times more days in the hospital and were four times more likely to be hospitalized over the course of a year than other children; 16% had been hospitalized during the previous year due to their condition (Newacheck & Halfon, 1998;

Newacheck & Taylor, 1992). Similar patterns of health care service use were found in Canada (McDougall et al., 2004).

In one survey, although children with special health care needs accounted for less than 16% of the child population, they accounted for 52.5% of children's hospital days, had more than twice as many visits to a physician, and had seven times as many visits to non-physicians as other children annually (Newacheck & Kim, 2005). Children with special health care needs were also found to be more likely to visit the emergency departments, use mental health care services, and access specialty and acute health care services than children without special needs (Szilagyi et al., 2003).

Children with special health care needs require a variety of services to manage their conditions, maintain their abilities, and promote their development. According to the U.S. Department of Health and Human Services, services most often required by this group include prescription medications (86% of children), preventive dental care (81% of children), and preventive medical care (78% of children). Some children with special health care needs also require eyeglasses or vision care (33%), mental health care (25%), and physical, occupational, or speech therapy (23%), and medical equipment (11%) or assistive mobility devices (4%). Children reporting more severe disabling conditions require more medical services; 47.1% need more specialized therapies such as physical, occupational, or speech therapy, and 62.8% need specialty medical care (U.S. Department of Health and Human Services, 2007). On average, children with special health care needs receive four medical services such as consumable medical products, assistive equipment, respite care, occupational therapy, physical therapy, and speech therapy, on a regular basis (Loughlin et al., 2004).

Vingilis, Wade, and Seeley (2007) investigated predictors of health care utilization among Canadian adolescents and found that adolescents reporting higher disability status and lower health status had higher rates of physician and non-physician utilization. In this study non-physician referred to nurses, chiropractors, physiotherapists, social workers, psychologists, occupational therapists, and other health care professionals. Perceived need of health care (as in the case of chronic health conditions and disabilities) was the strongest primary predictor of health care utilization among adolescents in Canada (Vingilis et al., 2007).

Because children with special health care needs use more health services, they generate higher medical costs than the average pediatric population (Neff, Sharp, Muldoon, Graham, & Myers, 2004). In the United States, children with special health care needs accounted for 76% of Medicaid expenses spent on children (Center for Health Care Strategies, 2000). Neff et al. (2004) found that the 9.5% of children in their sample identified as having a chronic condition accounted for 28.7% of all encounters with medical professionals and 45.2% of all medical expenditures. This translated to $15.4 million USD in health care expenses by children with special health care needs in 2004.

Using data collected in 1997 from the Medical Expenditure Panel Survey, Newacheck, Wong, Galbraith, and Hung (2003) found that adolescents with fair or poor health status had average annual expenditures of $1625.80, compared with $773.40 for adolescents with excellent or good health status. Similarly, adolescents with activity limitations had average annual expenditures of $1959.80 on health care services, compared with $705.20 for adolescents without activity limitations. Adolescents with

functional impairments and disabilities comprised 4% of the population studied, but accounted for 14% of health care expenditures (Newacheck et al., 2003).

Using data collected in 2000 from the Medical Expenditures Panel Survey, Newacheck and Kim (2005) found that children with special health care needs had average annual health care expenditures of $2099.00, which was more than three times the amount for children without special health care needs. Children with special health care needs had higher expenditures for hospital care, physician's services, non-physician services, and prescription medications than other children (Newacheck & Kim, 2005).

In summary, between 7.7% and 30% of children are identified as having a special health care need depending on the definition used, the sampling method employed, the country studied, and the time frame investigated (e.g., McDougall et al., 2004; Merrick, 2000). Due to their condition(s), children with special health care needs experience more disruptions in their daily functioning, miss more days of school, and spend more days ill in bed than their peers (e.g., Newacheck & Halfon, 1998). As a result, they have more frequent medical encounters, utilize more medical services, and generate higher medical expenditures than other children (e.g., Newacheck & Kim, 2005).

Despite their increased use of health services, little is known about whether adolescents with special health care needs, specifically those with physical disabilities, are satisfied with the health services they receive. Satisfaction with care is an important predictor of adherence to treatment and other positive health-related behaviors associated with improved health status (e.g. Sen et al., 2005) and subsequently, less health care usage and medical expenditures (e.g., Fotheringham & Sawyer, 1995). Because of these possible positive outcomes to both the individual and the medical system, it would be

beneficial to investigate whether adolescents with physical disabilities are satisfied with the care they receive in health care settings.

What is satisfaction?

A universal definition of patient satisfaction with health care is elusive as it pertains to various aspects of care and care settings, as well as patient expectations, perceptions, and experiences of care (Hornsten, Lundman, Selstam, & Sandstrom, 2005). Patient satisfaction has been defined as the "extent to which treatment gratifies the wants, wishes, and desires of clients" (Hirsh et al., 2005, p. 302); the "patients' subjective evaluation of their cognitive and emotional reaction to the interaction between their expectations about ideal care and their perceptions of the actual care received" (Eriksen, 1995; as cited in Hornsten et al., 2005, p. 611); and the "reflection of value judgments after a clinical experience or a series of assessments about medical care or treatment" (Sahin & Tatar, 2006, p. 172).

Why is satisfaction important?

Patient satisfaction with health care is an important indicator of the quality of health services (Donabedian, 1992; Thompson et al., 2009). So before further discussing satisfaction, it is important to understand which aspects of care are associated with quality health services. Donabedian (1988) identified three main areas of care that should be assessed when evaluating quality within the medical field: structure, process, and outcome. Structure refers to the characteristics of the setting in which care occurs. Structure of care includes attributes of material resources (facilities, equipment, money),

human resources (number and qualifications of professionals), and organizational structure (medical staff organization, peer review methods, reimbursement methods). Process of care refers to what is actually done in giving and receiving care; it includes patient activities in seeking and adhering to care, as well as practitioner activities in making diagnoses and implementing treatments. Outcome of care refers to the effects of care on the health status of patients; it includes increases in the patients' knowledge, changes in patients' behavior, and degree of satisfaction with care. These three aspects of quality of care are related to each other in that good structure increases the likelihood of good process, which increases the likelihood of good outcomes (Donabedian, 1988).

Because satisfaction has become an important indicator of the quality of health services (Donabedian, 1992; Thompson et al., 2009), health care providers are more frequently assessing patient satisfaction with the services they provide. In a survey of American health care professionals, 88% of respondents indicated that they routinely assess patient satisfaction with health care services and an additional 10% of respondents indicated that they planned to assess patient satisfaction within the coming year (Sen et al., 2005).

Within the past twenty years, research has focused on patient perceptions of the quality of health care they receive, and this information has often been used in developing policies of health service delivery and financing (Liptak et al., 2006). Patient satisfaction with the health care services they receive is associated with several positive health-related behaviors which are related to overall improved health outcomes (Sen et al., 2005). Satisfaction with health care services is important in determining whether patients seek treatment (Zastowny et al., 1989), make their own health-related decisions

(Law et al., 2003; Marelich & Murphy, 2003), maintain a relationship with their medical practitioner (Kaplan, Greenfield, & Ware, 1989; Riley et al., 2005), attend follow-up appointments (Freed et al., 1998; Litt & Cuskey, 1984), and adhere to treatment regimens (Hirsh et al., 2005; Litt & Cuskey, 1984; Martinez et al., 2012). Patient satisfaction with care is thus related to overall improved health outcomes (Marple, Kroenke, Lucey, Wilder, & Lucas, 1997; Sen et al., 2005; Squier, 1990).

Patient satisfaction with health care is complex because it is influenced not only by patient characteristics, expectations, and health status, but also by provider and health care setting characteristics. Identifying aspects of health care associated with increased patient satisfaction may inform health care professionals and assist in the development of more effective and efficient service delivery (King, Cathers, King, & Rosenbaum, 2001). Numerous studies have investigated the extent to which patients are satisfied with various aspects of health care services and have identified important features of the structures, processes, and outcomes of health care associated with satisfaction.

Studies investigating patient satisfaction with their health care services are often conducted to discover whether a specific group of patients are satisfied with a specific service offered by a specific health care facility. Although the information gathered in these studies may be useful to help improve service delivery at that specific health care facility, caution must be exercised when generalizing the findings of these research studies to other patient groups at other health care facilities.

Are adult patients generally satisfied with their health care?

Several studies have been conducted to determine the extent to which adult patients are satisfied with the health care services they receive. Patients receiving services for both acute and chronic conditions have been included as participants in these investigations and both groups have generally reported high ratings of satisfaction. McKim et al. (2007) surveyed patients treated at an Alberta emergency department for acute problems and found that 85% of patients were satisfied with the treatment they received. Patients receiving health services for chronic conditions also generally report being highly satisfied. All patients receiving treatment for diabetes at selected American health care centers were satisfied with the care they received; 75% reported their care was "good" while 25% reported their care was "very good" (Piette, 1999). Similarly, Bidaut-Russell et al. (2002) found that approximately 75% of patients with diabetes or rheumatoid arthritis rated their care as "excellent" and approximately 23% reported receiving "good" care at a health care facility in Minnesota.

When asked to rate their satisfaction with specific aspects of care, patients with various chronic conditions were generally highly satisfied with their access to care (DiMatteo et al., 1993), the information provided regarding their problem and treatment options (Hirsh et al., 2005), and interpersonal aspects of care (DiMatteo et al., 1993). In fact, patients attending Florida health clinics for chronic pain were more satisfied with interpersonal aspects of care than with pain relief or improvements in their condition, leading the authors to suggest that interpersonal processes of care may be more important to satisfaction than outcomes of care (Hirsh et al., 2005). This point is discussed in more detail later.

What affects patient satisfaction?

In addition to assessing the extent to which patients are satisfied with the medical care they receive, studies have identified several factors that influence patient satisfaction. Predicting satisfaction from patient demographic characteristics has produced mixed findings. Some studies have found that males are generally more satisfied than females (Bidaut-Russell et al., 2002; McKim et al., 2007) while others have found that females are more satisfied than males (Sahin & Tatar, 2006). Some studies have suggested that patient age is related to satisfaction, with older patients being more satisfied than younger patients (Bidaut-Russell et al., 2002; Sahin & Tatar, 2006) while others have not found such a relationship (Piette, 1999). Fan et al. (2005) found that higher patient education, better coping skills, and a more positive perception of their disease were each associated with greater satisfaction with care. Differences in methodology, patient diagnoses, and other sample characteristics underlie these conflicting findings.

Studies investigating the relationship of satisfaction with processes of care yield more consistent results. Satisfaction with care is more related to aspects and qualities of the patient-provider relationship than to patient characteristics (Sahin & Tatar, 2006). Patient satisfaction is related to interpersonal aspects of care - the way in which care is delivered.

Various relational factors associated with patient-centered care have been found to be related to patient ratings of satisfaction. Patient-centered care refers to patient-provider consultations in which the provider strives to understand the experience and expectations of illness, understand the whole person and find common goals, enhance the

interpersonal relationship, and use time realistically (Brown & Hanis, 1995). The cumulative findings of several independent studies indicate that patients reported being satisfied with care when they felt as though they were treated with respect and dignity, and as an equal partner in their own care (Harriott, Williams, & Peterson, 2005; Hornsten et al., 2005). Patients wanted to be treated as real people, rather than being treated as a case or a diagnosis (Hornsten et al., 2005). They reported that it was important for their health care provider to acknowledge the individuality of their needs, preferences, and opinions (Thorne et al., 2005). Patients who felt more involved in discussions of their care, more included in decision-making processes, and were more in agreement with their doctor regarding treatment goals were more satisfied with their care (Fuertes et al., 2007; Harriott et al., 2005; Hirsh et al., 2005; Hornsten et al., 2005).

Communication aspects of patient-centered care have also been related to satisfaction with health care. For example, patients receiving medical care for cancer reported that they wanted to know a great deal of information about their condition and treatment, even if this information was negative; receiving more information was related to increased satisfaction with care (Thorne et al., 2005). Similarly, Fan et al. (2005) found that patients receiving care for chronic conditions reported improved understanding of their disease and increased satisfaction with the encounter when they perceived health care professionals as explaining their disease using understandable language and providing them with sufficient information. Finally, Hirsh et al. (2005) found that patient communication with their health care provider about their condition was predictive of patient satisfaction with their health care experience.

Another aspect of health care associated with satisfaction is continuity of care. Continuity of care is a feature of patient-centered care that has been defined as "care over time by a single individual or team of health care professionals and to effective and timely communication of health information" (Cabana & Jee, 2004, p. 975). In a continuous care framework, health care providers become familiar with their patients' history, preferences, and opinions, and may be able to better manage chronic conditions effectively and monitor patients' progress over time (Cabana & Jee, 2004). Piette (1999) found that diabetes patients treated by the same doctor over time reported greater satisfaction with their choice of health care provider and were more satisfied with interpersonal aspects of their care. Continuity of care has been related to early diagnosis of illness, fewer hospitalizations, lower consumption of resources, reduced health care expenditures, and improved patient-provider communications and interactions (Cabana & Jee, 2004; van Servellen, Fongwa, & Mockus, 2006). Continuity of care is also an important aspect of patient-centered care because it is associated with increased patient satisfaction.

Why is parent satisfaction with their child's health care important?

Parents have often been surveyed regarding their satisfaction with the health care services received by their child. It is important to understand parental perceptions of satisfaction because parents are ultimately responsible for making decisions regarding the medical treatment of their children (King, Rosenbaum, & King, 1997). Parental satisfaction with their child's care is associated with engagement in treatment, treatment adherence, clinic attendance, continuation of treatment, continuity of care, and enhanced

parental functioning (Albrecht & Hoogstraten, 1998; Auslander, Netzer, & Arad, 2003; Riley et al., 2005). Parents who are satisfied report enhanced empowerment and self-efficacy in managing their child's condition; they also report feeling less stress and depression (Mitchell & Hauser-Cram, 2008; Summers, Hoffman, Marquis, Turnbull, & Poston, 2005). Because of these important outcomes, it is important to know the extent to which parents are satisfied with the health care services their child receives.

Are parents generally satisfied with their child's care?

Similar to studies investigating adult patient satisfaction, studies investigating parent satisfaction with their child's health care are often conducted to discover whether a certain group of parents is satisfied with a certain health care service offered to their child from a certain health care facility. Though the information gathered is useful to help improve service delivery at that specific health care facility, it is necessary to exercise caution when generalizing the findings of these research studies to other parent groups elsewhere. The findings of some of these research studies are discussed below, referencing results from specific parent groups where necessary and generalized findings where possible.

Numerous studies have investigated the extent to which parents are satisfied with their child's health services, and, similar to adult patients, parents generally report being satisfied with their child's care. Davis (1995) investigated satisfaction with emergency department services in Norfolk, Virginia and found that 95.7% of parents were satisfied with the care their child was given. Similarly, Petersen, Scherwath, Kruithoff, and Koch (2006) found that the majority of parents (approximately 85%) were satisfied with the

initial care given to their children at emergency departments in seven German hospitals following a traumatic brain injury. Parents of adolescents receiving outpatient care at a Teen Health Centre in Ohio reported being very satisfied with the overall services their child received, rating their satisfaction at 8.97 out of a possible score of 10 (Byczkowski et al., 2010). With respect to specific aspects of their child's care, 89% of parents felt they were given an opportunity to explain the reason for the visit, 94% were satisfied that the health care provider listened to their opinions, and 84% reported that the health care provider gave them understandable responses to their questions. Parents also reported feeling involved in decisions about their child's care and felt they were treated with respect and dignity (Byczkowski et al., 2010).

Parents of children with special health care needs are involved in the ongoing rehabilitation and treatment of their children (Galil et al., 2006), and several studies have investigated their satisfaction with the health care services provided to their child. Thompson et al. (2009) investigated perceptions of health care among parents of children with special health care needs by analyzing American data collected during the 2005-2006 National Survey of Children with Special Health Care Needs. During a telephone interview, parents were asked to report whether they were or were not 'usually' or 'always' satisfied with their child's health care services within the previous year. It is important to note that parents were asked about overall aspects of their child's health care services and that data were collected from a large and diverse sample of parent participants (N = 40,723) residing in multiple states, experiencing variation in access to services, and availing of different health insurance options. The authors identified that 59.8% of parents reported that they were 'usually' or 'always' satisfied with the overall

health care services their child received; parents without private health insurance were less likely to be satisfied with their child's care (Thompson et al., 2009). While this research was large-scale and provided insight into parents' overall perceptions of care, studies that have focused specifically on parental satisfaction with interpersonal aspects of care (e.g., family-centered care, parent-provider communication) have generally yielded higher satisfaction ratings, as discussed below.

In a study including parents of children both with and without special health care needs, parents reported being very satisfied with the communication skills and the expertise of their child's physician (Burstein et al., 2005). In an emergency department setting for their child's asthma care, more than 80% of parents were satisfied with the communication of medical information by the provider; parents reported that this information was clear and helpful and that they were given opportunities to ask questions (Wissow et al., 1998). Similarly, Wood et al. (2009) found that 90% of parents of children with special health care needs were satisfied with their communication with their child's care provider at their pediatrician clinic.

In addition to communication, parents of children with special health care needs have reported feeling satisfied with their interpersonal relationship with their child's health care provider. Satisfied parents felt that providers cared about their family, were interested in their lives, and were willing to collaborate with the family regarding treatment options (Galil et al., 2006). In a pediatric setting, 87% of parents were satisfied with their interactions with clinic staff and 83.6% were satisfied with their involvement in decision-making (Wood et al., 2009). In another study involving seven health care facilities in the United States, 97% of parents felt respected by their child's health care

provider, especially regarding cultural issues (Riley et al., 2005). Parents have also been found to report a high degree of trust in their child's health care provider (Chen & Boothroyd, 2006) and be satisfied with the child- and family-focused nature of their patient-provider relationship (Summers et al., 2005).

What affects parent satisfaction?

Several factors are predictive of parental satisfaction with the health care services their child receives. Studies investigating parent demographic characteristics have suggested that older parents, those with lower incomes, those with decreased stress and depression, those who were married, and those with lower education levels were more satisfied with their child's care (Heflinger, Simpkins, Scholle, & Kelleher, 2004; Mitchell & Hauser-Cram, 2008; Summers et al., 2005). Other studies have found that child characteristics were important to parental ratings of satisfaction. Specifically, younger children, those with milder delays or conditions, those with fewer behavior problems, and those with higher functioning generally had parents who were more satisfied and had greater trust in health care providers (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Chen & Boothroyd, 2006; Mitchell & Hauser-Cram, 2008; Summers et al., 2005; Thompson et al., 2009).

Similar to the way in which patient-centered care was important to adult patients' satisfaction, characteristics of family-centered care were important to parents' satisfaction with their child's health care services (Law et al., 2003). Family-centered care refers to a philosophy and method of service delivery for children and parents that emphasizes a partnership between parents and service providers, focuses on the family's role in

decision-making about their child, and recognizes parents as the experts on their child's status and needs (Kuo, Bird, & Tilford, 2011; Rosenbaum, King, Law, King, & Evans, 1998). Parents who reported experiencing family-centered care reported greater satisfaction with health care services (Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006), improved coordination of services (Turchi et al., 2009), more stable child health status, and decreased emergency room utilization (Kuo et al., 2011). Family-centered care seems clearly associated with positive child health and family outcomes.

Parents have indicated that one aspect of family-centered care important to their satisfaction is their relationship with their child's health care provider. Specifically, parents have reported that they want a partnering relationship in which they are included in their child's care and participate in the treatment of their child's condition (Baine, Rosenbaum, & King, 1995; King, Rosenbaum, & King, 1996; Riley et al., 2005). In addition to increased satisfaction with health care services, parent perceptions of a family-provider partnership have been associated with reports of having organized health services in place, preparedness for transition to adult services, reduced emergency room visits for their child, and fewer missed days of school (Knapp et al., 2010). Parent-provider relationships that are caring, enable the provision and sharing of information, and offer clear, adequate, and thorough explanations regarding their child's condition and treatment have been identified as satisfying to parents (Baine et al., 1995; Davis, 1995; Galil et al., 2006; Garwick, Kohrman, Wolman, & Blum, 1998; King et al., 1997). Relationships in which care is perceived as individualized, respectful, reassuring and supportive have been predictive of higher parent satisfaction with their child's health care

services (Garwick et al., 1998; King et al., 1996; King et al., 1997; Mitchell & Hauser-Cram 2008).

Continuity of care is another aspect of family-centered care that has been predictive of parental satisfaction. Health care services that are coordinated, comprehensive, consistent, and continuous have been associated with higher parental ratings of satisfaction (Baine et al., 1995; King et al., 1997; Law et al., 2003). As discussed earlier, children with special health care needs avail of many health services and parents are often responsible for coordination among services, including scheduling primary and specialty appointments, dealing with educational components, and seeking community resources for their child (Lawson, Bloom, Sadof, Stille, & Perrin, 2011). This often results in increased parental stress (Wood et al., 2009). Receiving care-coordination assistance is associated with higher ratings of parental satisfaction with services, fewer issues receiving referrals for specialty care, increased utilization of primary and specialty care, and greater likelihood of experiencing family-centered care and family-provider partnerships (Kuo et al., 2013; Lawson et al., 2011; Turchi et al., 2009). Galil et al. (2006) suggested that continuity of care may foster greater collaboration and communication in the relationship between parents and health care providers, and such improvements in the relationship contribute to satisfaction with care. Care delivered from a continuity of care framework may enable features of family-centered care to develop, and thus enhance parental satisfaction with care.

Are adolescents satisfied?

Adolescents are also users of the health care system; however very few studies have been conducted to investigate whether they are satisfied with the services they receive. Litt and Cuskey (1984) found that adolescents (mean age = 14.9 years) were moderately satisfied with the health care delivered at an adolescent health clinic at Stanford University; 61.9% of adolescents surveyed were satisfied while 38.1% were dissatisfied with the care they received. Freed et al. (1998) found that most adolescents aged 12 to 21 years were satisfied with their health care appointments at an adolescent health care clinic and reported high satisfaction ratings. In addition to high ratings of overall satisfaction with outpatient care at a Teen Health Centre, Byczkowski et al. (2010) found that most adolescents reported satisfaction with their involvement in decisions about their care, their communication with their health care provider, and their provider's ability to treat them with respect and dignity. It must be noted that these studies included only adolescents with acute medical conditions and omitted those with special health care needs.

To understand whether adolescents with chronic conditions were satisfied with their care, Shaw, Southwood, and McDonagh (2006) investigated satisfaction with health care services among adolescents aged 11, 14, and 17 years diagnosed with juvenile idiopathic arthritis. Using a 22-item questionnaire, participants were asked to rate their perceptions of 'best' and 'current' care practices regarding the health care services they received. Areas of care assessed included the provision of honest information, patient-provider communication, coordination of care, confidentiality, staff knowledge, and understanding of adolescents. Overall, adolescents reported being satisfied with the

provision of services they were receiving, but their ratings were significantly lower than their expectations of 'best' practice for all but two questionnaire items ('display of relevant health-related information' and 'opportunity to be seen alone'). Adolescents were satisfied with their health care services, but felt there were opportunities to improve service delivery in most areas of care assessed (Shaw et al., 2006).

In another study, Mah et al. (2006) investigated whether adolescents with neurological diseases treated at the Alberta Children's Hospital were satisfied with the health care services they received. Eighty-three percent of adolescents reported that they were either 'somewhat satisfied' or 'very satisfied' with their care; they reported being satisfied with information sharing, communication, and teen centered service aspects of care. Adolescents were less satisfied with aspects of the patient-provider relationship, and noted that providers should be more supportive and respectful, especially regarding their independence (Mah et al., 2006).

What affects adolescent satisfaction?

In addition to investigating whether adolescents are satisfied, studies have investigated factors that are predictive of satisfaction with health care services. Adolescent patient characteristics such as age and gender have not been consistently predictive of satisfaction. For example, Litt and Cuskey (1984) found that females and adolescents older than fifteen years of age were more satisfied with their care, however Freed et al. (1998) found no such association between satisfaction and patient characteristics. Both Shaw et al. (2006) and Mah et al. (2006) found that neither

diagnosis, nor disease severity, nor family income, nor parents' marital status were predictive of adolescents' satisfaction with health care services.

Although such patient characteristics were not predictive of satisfaction, characteristics of the patient-provider relationship associated with patient-centered care were found to be predictive of adolescent satisfaction. For adolescents receiving acute care services, the provider's interaction style was a more important predictor of satisfaction than the content of their discussions; that is, *what* the provider chose to discuss was less important than the *way* in which the provider conveyed that they knew and cared about the adolescent (Freed et al., 1998). In a different study, adolescents indicated that maintaining confidentiality, respecting modesty and privacy, and explaining the rationale for testing and results were important factors associated with their satisfaction (Litt, 1998).

Adolescents with chronic health conditions have also indicated that aspects of the patient-provider relationship are important to their satisfaction with care, and these aspects are more important to them than aspects of the physical environment or other health care processes (Shaw et al., 2006). Adolescents were more satisfied when providers were honest with them about condition prognoses and treatment options, without 'shielding' them from potentially upsetting information (Shaw et al., 2006; van Staa, Jedeloo, & van der Stege, 2011). Adolescents indicated that provider qualities such as being trustworthy, honest, caring, understanding, and respectful were important to their satisfaction and their perceptions of quality services (Biering & Jensen, 2011 Britto; et al., 2004; van Staa et al., 2011).

In one study, adolescents with chronic neurological disease indicated a need for improvement in their communications with health care providers (Mah et al., 2006). Similarly, children with cerebral palsy indicated a desire to be included and informed regarding their care (Garth & Aroni, 2003). They valued direct communication with their physician and wanted the doctor to ask them questions directly and to provide an opportunity for them to ask questions; they also wanted to be informed about the medical procedures being performed (e.g., taking their temperature) and the treatment options available to them (Garth & Aroni, 2003). The preference to have direct communication with their health care provider has also been reported in adolescents with other chronic health conditions; adolescents prefer discussion about their health condition to be directed to them (Britto et al., 2004; Shaw et al., 2006; van Staa et al., 2011) rather than to their parents. Overall, aspects of the patient-provider relationship associated with patient-centered care are important to the satisfaction of children and adolescents with chronic conditions.

In addition to aspects of the patient-provider relationship, adolescents reported that provider expertise and knowledge about their condition was important to their satisfaction. Adolescents reported that they preferred providers who were highly knowledgeable about their health condition, who demonstrated good practical skills (e.g., giving injections), and who had extensive experience treating individuals with their condition (Britto et al., 2004; Shaw et al., 2006; van Staa et al., 2011). Adolescents value both interpersonal and technical qualities of their health care provider.

Are there differences in parent and adolescent perceptions of satisfaction?

Parents are generally satisfied with the care their children receive and adolescents are generally satisfied with the care they receive. It is important to know, however, the extent to which adolescents report similar ratings of satisfaction as their parents. It is also important to know the extent to which adolescents value similar aspects of care as their parents.

Although parents and their children generally report high ratings of satisfaction, numerous studies have found that parents are more satisfied than children and adolescents (Barber, Tischler, & Healy, 2006; Byczkowski et al, 2010; Chesney, Lindeke, Johnson, Jukkala, & Lynch, 2005; Mah et al., 2006; Naar-King, Siegel, & Smyth, 2002; Sonneveld, Strating, van Staa, & Nieboer, 2012). Naar-King et al. (2002) found that 94% of parents were satisfied with their communication with health care providers, while only 81% of children and adolescents were satisfied with aspects of communication and felt that their health care providers listened to them. Comparable results were reported by Byczkowski et al. (2010), who found that 84% of parents but only 72% of adolescents were satisfied with receiving understandable answers to their questions.

Mah et al. (2006) found that adolescents were less satisfied than their parents with issues of open communication, privacy, and confidentiality. Adolescents were less satisfied than their parents regarding care providers' abilities to communicate with adolescents, to talk and listen to them, to understand the realities of being an adolescent, and to provide them with honest information (Shaw et al., 2006; Sonneveld et al., 2012). Adolescents reported being less satisfied than parents regarding their ability to make decisions about who was permitted to come into the examination room (Shaw et al.,

2006) and to discuss issues with care providers privately without parents present (Sonneveld et al., 2012). Communication with their health care provider and issues of privacy were identified as particularly salient aspects of care for adolescents' transitions to adult services and condition self-management.

Perhaps the most important difference between parent and child and adolescent perceptions was with respect to involvement, where 92% of parents, but only 61% of children and adolescents were satisfied with their level of involvement with treatment decision-making (Naar-King et al., 2002). Byczkowski et al. (2010) also found differences between parents and adolescents regarding involvement, with 83% of parents but only 73% of adolescents reporting being satisfied with their involvement in their decisions about care. Children and adolescents indicated that they wanted to be involved in their treatment processes, but reported less satisfaction and fewer opportunities to be involved in their own health care (Lipstein, Muething, Dodds, & Britto, 2013; Naar-King et al., 2002; Sonneveld et al., 2012).

In a series of qualitative studies, Mitchell and Sloper asked children with special health care needs and their parents to identify factors they felt were indicative of quality medical care. They found that, although parents and their children indicated several similar characteristics associated with quality and satisfaction, the specific features that each group identified as important were different. For example, parents and children both stated that staff knowledge and training, having needs met, and open and respectful relationships were important to quality care. But while parents reported that it was important for health care professionals to be able to provide information, children and adolescents reported that it was important that providers understand all aspects of their

illness and be able to take care of them properly (Mitchell & Sloper, 2003). Parents also stated that it was important that providers listen to and respect the needs of the whole family and their culture, but children and adolescents were more concerned that staff respect their ideas and value their opinions about their illness and treatment plan; children wanted to be able to be included in the decision-making processes of their care (Mitchell & Sloper, 2003).

Clearly, parent and child perceptions of important features of quality of care were similar, but they identified different priorities in each area. Overall, children and adolescents were concerned with everyday issues of relationships with professionals and peers, while parents were more concerned with issues of knowledgeable staff and continuity of care for their children (Mitchell & Sloper, 2001).

These studies suggest that parents' opinions may not be accurate substitutes for their child's opinions about aspects of medical care that are important. Other studies have found that there is often agreement between parents and adolescents regarding observable aspects of health, such as physical limitations, but there is less agreement regarding subjective evaluations, such as emotional health-related quality of life (Eiser & Morse, 2001; Theunissen et al., 1998). Satisfaction with health care services is subjective; therefore health care providers should not assume that parents are appropriate proxies for their children. Adolescents should be asked directly about their preferences and be more included in the medical encounter.

Are adolescents involved in discussion of their health care?

Communication with a health care provider has been identified as important to quality services by adult patients, parents of child patients, and children with special health care needs. Studies have looked at communication patterns between doctors, parents, and child patients to determine how the individuals interact, participate, and contribute to the medical visit.

Children have usually been left out of communication within the medical encounter, with parents and providers doing most of the talking. In a review of the communication literature, Tates and Meeuwesen (2001) found that doctors spoke for approximately 60% of the time during a medical visit, while parents spoke for 26-39% of the time and children spoke for only 2-14% of the time. In fact, van Dulmen (1998) found that in 36% of pediatric medical consultations children did not verbally participate at all!

In addition to differences in the amount of time providers, parents, and children spent talking during a medical encounter, studies have also indicated differences in the content of the communication. Specifically, doctors showed instrumental communication when directing their speech toward a parent by providing information and instructions, but were more affective and displayed more social behavior and joking when directing their speech toward children (Tates & Meeuwesen, 2001). Providers mainly obtained information from children, but gave information to parents (Tates & Meeuwesen, 2001; Wissow et al., 1998). Most of parents' speech during a medical encounter involved giving medical information to their child's provider. Similarly, children mostly gave

medical information to their provider, but otherwise rarely spoke and were often passive participants throughout the visit (Wissow et al., 1998).

As discussed earlier, children with special health care needs use the medical system more frequently than other children and, as a result, have more encounters with health care professionals. Furthermore, children with special health care needs must develop the skills necessary to participate in their own medical care as they transition from pediatric to adult health care (Sonneveld et al., 2012; Tates, Elbers, Meeuwesen, & Bensing, 2002). Therefore, it is very important that they, along with their parents, be included in conversations regarding their health care.

Burstein et al. (2005) conducted a study to see whether there were differences in communication patterns during a medical visit involving children either with or without special health care needs. The authors found similar communication patterns as those observed in previous studies: doctors spoke the most, followed by parents, and then children. There were no differences in doctor communication based on whether the child in the medical visit had or did not have a special health care need. However, parents and children with special health care needs were more involved throughout the consultation than their healthy counterparts. Parents of children with special health care needs spoke to the provider more than the parents of healthy children and most importantly, children with special health care needs spoke more during their consultation than did other children. Children's speech toward their provider included social exchanges, such as joking, as well as discussions of medical issues and concerns. It must be noted, however, that although children with special health care needs were more involved in discussions of their care, they were less involved than their parents and their doctors.

Children with special health care needs are more involved in medical consultations than their healthy counterparts, but they are still less involved than their parents (Burstein et al., 2005). Following this line of study, Lipstein et al. (2013) investigated treatment decision-making of adolescents with chronic conditions. The authors interviewed adolescents regarding their participation in making condition-related decisions and their perceptions about how medical treatment decisions were made. Adolescents reported that parents often had significant roles in the decision process, including researching about the treatments, discussing options and asking questions of health care providers, and making the final decision about treatments. Health care providers were involved by providing information about the treatment options and answering questions posed by parents and adolescents. Participants felt that they were included in the treatment decisions, usually near the end of the process after parents had indicated their preferences. Adolescents reported that they were satisfied about how treatment decisions were made, but that they would have preferred a different role in the decision process. Adolescents with chronic conditions valued the involvement of parents and health care providers, but would prefer to have more involvement in the treatment decision-making process.

What is treatment adherence?

Treatment adherence has been defined as an active, voluntary, collaborative involvement of the patient and their health care provider in a mutually acceptable course of behavior to produce a desired preventative or therapeutic result (Meichenbaum & Turk, 1987, as cited in Sawyer & Aroni, 2003). Treatment adherence is often

conceptualized as taking medication, but it also includes other health-promoting behaviors such as treatment regimens (e.g., physiotherapy), practices to monitor or alleviate symptoms of disease (e.g., glucose testing) or health promotion practices (e.g., weight loss or smoking cessation; Sawyer & Aroni, 2003).

The terms treatment adherence and treatment compliance are sometimes used interchangeably within the research literature to generally refer to the extent to which a patient follows a health care regimen (Sawyer & Aroni, 2003). However, the term treatment adherence is preferred as it implies that the patient and provider agree on the treatment regimen (Sawyer & Aroni, 2003) and it emphasizes the therapeutic relationship between the two parties (Kyngas, 1999).

Why is treatment adherence important?

Perhaps the most important result of patient satisfaction with health care is adherence to treatment regimens. Treatment prescriptions are meant to enhance patients' health status, to maintain and control their condition, and to prevent the deterioration or progression of their disease (Abbot & Gee, 1998). In addition to correct diagnosis and choice of treatment, it is assumed that adherence to treatment is necessary to improve health and successfully manage disease (Sawyer & Aroni, 2003). Therefore, non-adherence to treatment is likely to be associated with increased cost to the patient regarding progression of their disease, and increased cost to the health care system regarding the expense of treating more severe illness. Patient satisfaction is related to improved treatment adherence (e.g., Litt & Cuskey, 1984), which is related to improved

health outcomes. Hence, it is necessary to understand satisfaction of patients with their health care services in order to enhance their overall health outcomes.

What are some barriers to treatment adherence?

Despite the importance of patient adherence to treatment regimens, many patients do not adhere to their treatment plans even when their conditions may be life-threatening. Recent studies have found that only 32% of epilepsy patients were adherent to treatment, up to 66% of asthma patients were non-adherent, and 58% of renal dialysis patients showed poor treatment adherence (Abbott & Gee, 1998). Adults with cystic fibrosis reported numerous reasons for non-adherence to treatment, including social reasons (e.g., interferes with social life, embarrassing to take medications in public), time reasons (e.g., takes too long, forgetting, too busy), and emotional reasons (e.g., resentment, feel different from friends; Abbott & Gee, 1998).

While there are numerous studies investigating adult patient treatment adherence, fewer studies have investigated treatment adherence in children and adolescents. Kyngas (1999) found that nearly half (42%) of adolescents with asthma reported complete adherence to their treatment regimens, 42% reported satisfactory (partial) adherence, and 18% reported poor adherence. The author concluded that listening to patients and tailoring treatments to individuals' needs were factors associated with better adherence to asthma treatments. Martinez et al. (2012) investigated stigma associated with their condition as a possible barrier to treatment adherence among adolescents; this refers to the negative reaction to an attribute (e.g., a physical deformity, behavior, etc.) in an individual that is deemed undesirable in a social setting. In this study, adolescents who

reported good treatment adherence also reported having a good relationship and receiving support from their doctors (99%) and nurses (98%). Adolescents who reported poor adherence reported receiving less support from their doctors (12%) and nurses (12%) and also reported a poor sense of normality (47%). Thus it seems as though their relationship with health care providers influences adolescents' treatment adherence. This is discussed in more detail below.

How is treatment adherence related to satisfaction?

Patient satisfaction is related to improved treatment adherence, which is related to improved health outcomes. Litt and Cuskey (1984) found that adolescents who were satisfied with their health care providers were more likely to attend follow-up appointments – one aspect of adherence. However, Freed et al. (1998) found that adolescents' satisfaction with their health care provider was only associated with their intention to attend follow-up appointments, not with their actual appointment attendance. Freed et al. (1998) provide several explanations as to the differences in these findings. Firstly, very few adolescents scheduled follow-up appointments, thus limiting the statistical power of the results. Secondly, returning for the appointment may not have been under the adolescents' control. Finally, the reason for the initial appointment may have been resolved and no follow-up appointment was required.

Martinez et al. (2012) investigated the impact of condition-related stigma on medication adherence in adolescents diagnosed as HIV-positive. Adherence to medication regimes is particularly important for this population because it has been associated with the disease becoming chronic and manageable rather than lethal. The

authors reported that satisfaction with health care providers impacted on adolescents' treatment adherence. Specifically, when adolescents' ratings of satisfaction were low, stigma negatively affected medication adherence, but when adolescents' ratings of satisfaction were high, the effects of stigma were diminished and adolescents were more likely to adhere to medication regimes. Satisfaction with health care providers minimized the effect of stigma on adolescents' treatment adherence.

These studies collectively suggest that adolescent satisfaction with health care services is associated with intention to attend follow-up appointments and adherence to treatment. If adolescents are not satisfied with the services they receive, it may translate into failure to receive adequate medical care for their condition, which could result in the deterioration of their health status (Abbott & Gee, 1998; Martinez et al., 2012). Therefore, it is necessary to know whether adolescents are satisfied with the health care services they receive and to identify which factors they feel are associated with higher quality of care.

Why this study?

There is little information regarding important indicators of quality of medical care to adolescents. Many studies have focused on adult patient perceptions of health care and the factors they associate with higher quality of services. Very few studies have investigated quality of care involving adolescents and even fewer studies have directly included adolescent participants. Most studies involving this population usually report parent perceptions of their child's care. This makes it difficult to understand which

factors adolescents deem as important and to determine the extent to which adolescents are satisfied with the health care services they receive.

Adolescents with special health care needs are frequent and chronic users of the health care system. They utilize more health services and account for more health care expenditures (Newacheck & Kim, 2005; U.S. Department of Health and Human Services, 2007), yet they have often been left out of conversations about their care (Wissow et al., 1998). Although satisfaction is important to various health outcomes and improvements, it is unknown whether adolescents with physical disabilities are satisfied with their health care. Therefore, the current study sought to use quantitative measures in order to investigate the perceptions of health care of adolescents with chronic physical disabilities by examining four research questions: (1) To what extent are these adolescents satisfied with the health care they receive? (2) Which aspects of care do adolescents identify as important to their satisfaction with care? (3) How similar are adolescent perceptions of care to those of their parents? (4) Do adolescent perceptions of care relate to their intentions to adhere to treatment plans?

Based on the previous research findings, it was predicted that (1) Adolescents would be satisfied with the health care services they received, (2) Adolescents would identify that interpersonal processes of health care were important to their satisfaction; and information-sharing and communication would be particularly important, (3) Adolescents' parents would report that they were satisfied with health care, although they would be satisfied with different aspects of care than their adolescents, (4) Satisfaction with health care would be predictive of adolescents' reported intentions to adhere to treatment recommendations.

METHOD

Participants

A convenience sample of adolescents was recruited to participate in this study from pediatric rehabilitation clinics at a provincial children's health centre between January 2008 and August 2008. Adolescents were considered eligible to participate in this study if they were between the ages of 11 and 19 years, had been diagnosed with a physical disability, and were receiving services from the rehabilitation department (N = 29). Potential adolescent participants who did not attend their clinic appointment (n = 4) or who chose not to meet with the researcher (n = 2) did not participate in this study. All adolescents who met with the researcher to receive more information about the study agreed to participate (n = 23; 79.3% of potential participants). One adolescent was not cognitively able to complete a rating scale (determined during screening) and was excluded from the study. Another male adolescent, aged 15 years, chose to complete only the demographics questionnaire; his demographic data are reported but were not included in subsequent analyses. Therefore, n = 22 (75.8% of potential participants) completed the demographics questionnaire and n = 21 (72.4% of potential participants) completed all questionnaires to participate in this study.

After adolescents agreed to participate in the study, their accompanying parent(s) was (were) also invited to participate. From a total of 23 parents invited to participate, 22 parents agreed to complete the questionnaires. Twenty of the parent questionnaires were completed by mothers, and one questionnaire was completed by both mother and father together; thus a total of 21 parent questionnaires were completed. One parent completed the questionnaires but their child chose not to participate, and another

adolescent completed the questionnaires but their parent was not present and thus did not participate. Twenty adolescent-parent pairs completed all questionnaires. Adolescent and parent participation is illustrated in Figure 1.

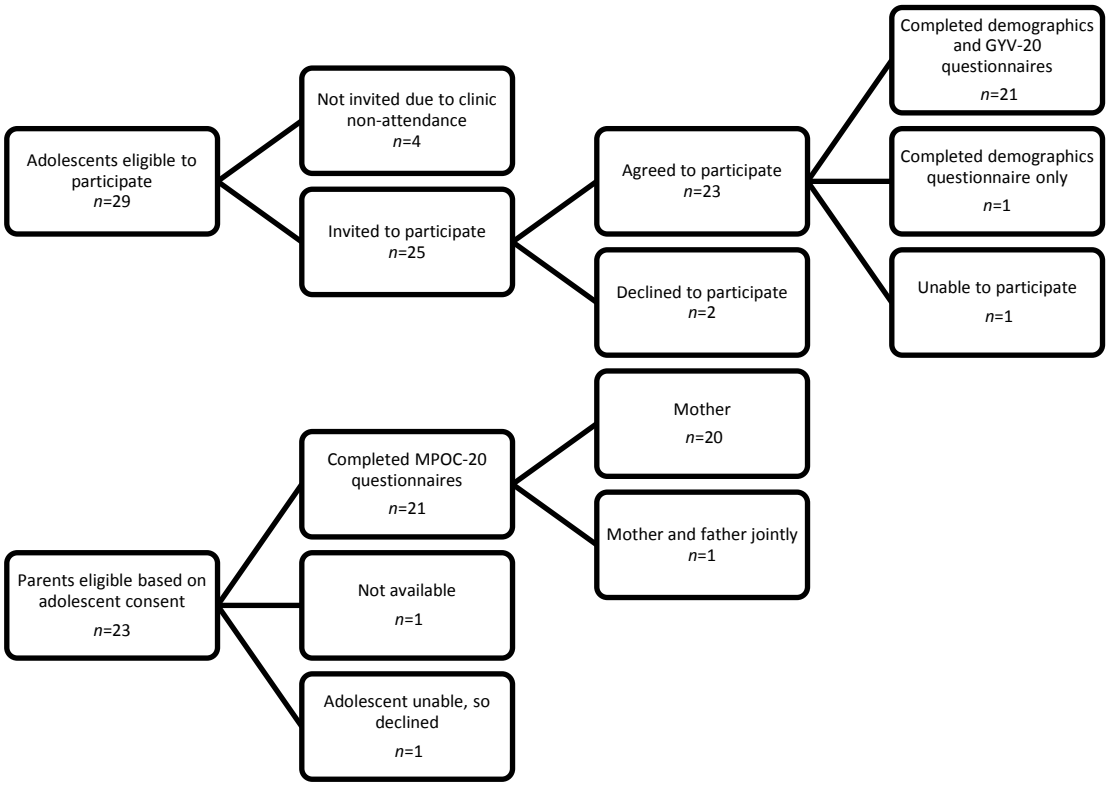

Figure 1. Adolescent and parent study participation information.

Adolescents' demographic characteristics are presented in Table 1. Fourteen females (66.7%) and eight males (33.3%) aged 11 to 19 years[1] (mean = 15 years, *sd* = 2.49) completed the demographic questionnaire. The distribution of participant age is represented in Figure 2. When asked about their place of residence, 50% of adolescents reported that they lived in rural communities and 50% reported that they lived in the

[1] The developmental period of adolescence corresponds to the period between ages of 10 and 19 years (Canadian Paediatric Society, Age Limits and Adolescents, 2014).

urban centres of the St. John's area (36.4%) and Corner Brook (13.6%) in the province of Newfoundland and Labrador.

Table 1

Adolescent Demographic Characteristics

Characteristic	Number of Participants	%
Gender		
Male	8	33.3
Female	14	66.7
Town		
St John's area	8	36.4
Rural	11	50.0
Corner Brook	3	13.6
Diagnosis		
Spina Bifida	11	50.0
Cerebral Palsy	8	36.4
Other	3	13.6
Mobility		
Walk independently without assistance	12	55.0
Use mobility assistance devices	10	45.0

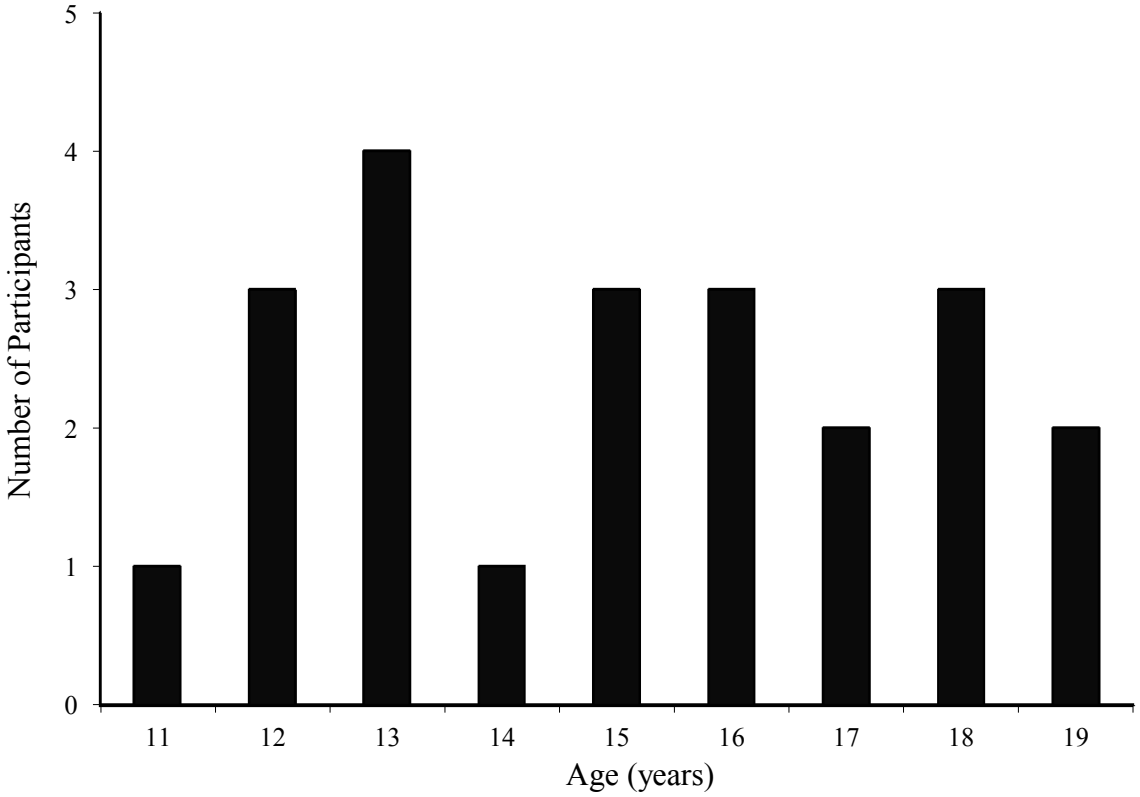

Figure 2. Number of adolescents according to age (years).

Adolescents reported that they had been diagnosed with spina bifida (50%), cerebral palsy (36.4%), and other disabling conditions (13.6%); comorbid conditions were not reported. Adolescents perceived the severity of their disability to range from mild to severe (range = 1-7, mean = 3.39, *sd* = 1.73). The distribution of adolescents' ratings of the severity of their condition is represented in Figure 3. Twelve adolescents (55%) reported that they were able to walk independently without the use of mobility devices, while 10 adolescents (45%) reported using assistive mobility devices. All

adolescents were currently receiving rehabilitation services and had been receiving such services for most of their lives.

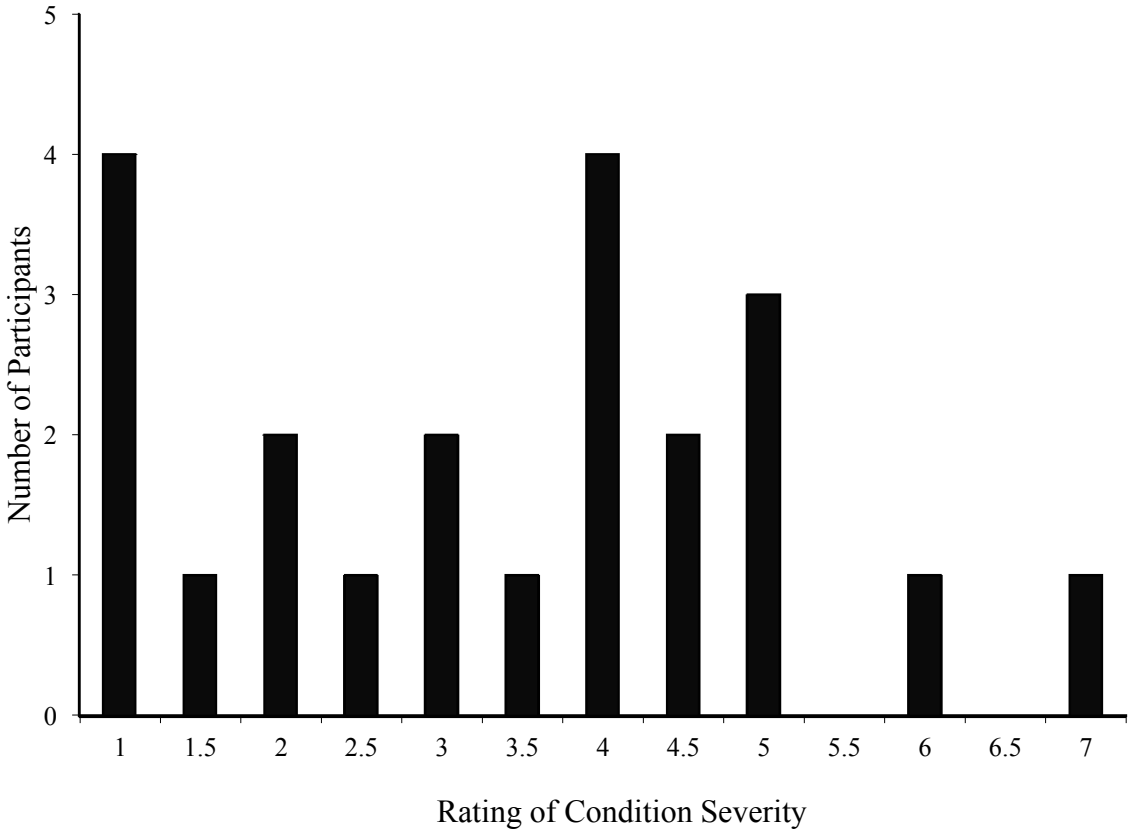

Figure 3. Number of adolescents rating the severity of their condition at each point of a Likert rating scale (1=mild, 7=severe).

Measures

Measure of Processes of Care

Parent participants completed the "Measure of Processes of Care" (MPOC-20; King, King, & Rosenbaum, 2004) which was designed to assess parents' perceptions of the quality of care their children receive from medical professionals and treatment

centres. The MPOC-20 assesses parental satisfaction with five domains of their child's health care: enabling and partnership, providing general information, providing specific information, coordinated and comprehensive care, and respectful and supportive care. All twenty items of this questionnaire are introduced by the general phrase "To what extent do the people who work with your child…" and each item describes the behavior of medical care providers (e.g., "…fully explain treatment choices to you"). Parents were asked to rate the extent to which they agreed with these statements along a 7-point Likert scale (1 = never, 7 = to a great extent). This questionnaire is referred to here as the MPOC-20 (Satisfaction).

In addition, a second version of this measure was used to assess the *importance* of each aspect of care to parents, by modifying the introductory phrase and scale descriptors. In this version, the same twenty items were introduced by the general phrase "How important is it to you that the people who work with your child…", followed by the description of the behavior of medical care providers (e.g., "…fully explain treatment choices to you"). Parents were asked to rate the importance of these characteristics of medical care along a 7-point Likert scale (1 = not important, 7 = very important). This questionnaire is referred to as the MPOC-20 (Importance).

The MPOC-20 (Satisfaction) has been shown to have high internal consistency (Chronbach's alpha = 0.83 to 0.90) and moderate concurrent validity with the Client Satisfaction Questionnaire (r = 0.41 to 0.61), another measure of satisfaction with health care services (King et al., 2004). As the MPOC-20 (Importance) is an adaptation developed for this study, there was no prior information concerning its psychometric properties.

Giving Youth a Voice

"Giving Youth a Voice" (GYV) is a measure that assesses adolescents' perceptions of the client-centredness of services for youth with disabilities (Gan, Campbell, Snider, Cohen, & Hubbard, 2008). It focuses on adolescents' overall experiences rather than experiences with individual service providers. This instrument was initially developed based on the MPOC so as to be appropriate for use with adolescents and thus assesses similar domains of satisfaction with health care. The GYV was further developed based on feedback from focus groups of adolescents receiving rehabilitation services at a major Canadian pediatric rehabilitation centre. Four major themes of care were identified (discussed below), and a 56-item questionnaire (GYV-56) was developed. The GYV-56 was found to have good internal reliability (Cronbach's alpha = 0.71 to 0.88), test-retest reliability (Cronbach's alpha = 0.88 to 0.96), and construct validity with the Client Satisfaction Questionnaire (r = 0.39 to 0.61; Gan et al., 2008). This measure was subsequently shortened to twenty items (GYV-20) to improve its user-friendliness (Campbell, Gan, Snider, & Cohen, 2003).

The GYV-20 questionnaire has 20 items that assess four areas of medical care including supportive and respectful relationships, information sharing and communication, supporting independence, and teen centered services. All items of this measure are introduced by the phrase "How much do the people who work with you…" and each item describes the behavior of medical care providers (e.g., "…talk to you honestly?") The GYV-20 asks adolescents to rate their satisfaction with these interpersonal aspects of health care along a 7-point Likert scale (1 = never, 4 = sometimes, 7 = a lot). This questionnaire is referred to as the GYV-20 (Satisfaction).

In addition to using the GYV-20 to assess satisfaction, adolescents completed a modified version of the GYV-20 to rate the importance of aspects of medical care. All items of this 20-item questionnaire were introduced by the phrase "How important is it that the people who work with you…" and each item described the behavior of medical care provider (e.g., "…talk to you honestly"). Adolescents responded to these items using a 7-point Likert scale (1 = not important, 4 = somewhat important, 7 = very important). This questionnaire is referred to as the GYV-20 (Importance).

Because the GYV-20 is continuing to be developed, there are few studies that provide reports of its reliability and validity. Preliminary reports have found that the GYV-20 has comparable psychometric properties to the previous 56-item version of the measure (Campbell et al., 2003). A study conducted in the Netherlands using a Dutch translation of the GYV-20 found good internal consistency (Cronbach's alpha = 0.76 to 0.81) and test-retest reliability (Cronbach's alpha = 0.82 to 0.92), and modest correlations with ratings of overall satisfaction (r = 0.52 to 0.61; Siebes et al., 2007).

"More About You" Questionnaire

The "More About You" questionnaire developed for this study asked adolescents to provide demographic information, such as age, gender, residence (urban or rural), type and severity of disability, and use of assistive devices. The questionnaire also included items pertaining to participants' intentions to adhere to treatment recommendations and two open-ended questions to assess the aspects of their care with which adolescents were most satisfied and areas that they felt should be improved.

Procedure

During the week before each clinic, a staff psychologist contacted the researcher and indicated the initials and ages of potential adolescent participants scheduled to attend the clinic. During the clinic, the researcher provided this list of potential participants to clinic staff members and waited in the waiting room. Staff members then informed adolescents and their parents that they were candidates for a research study. Eligible patients and their parents were told that a student from the Psychology Department at Memorial University of Newfoundland was conducting a study with youth attending the rehabilitation clinics and that participation involved completing some questionnaires. Adolescents and their parents were asked if they would like to learn more about the study by talking with the researcher. If they chose to do this, adolescents and their parents met with the researcher to review the information letter and ask questions pertaining to the study. Participant forms are included in Appendix A.

All participants were informed that their participation was completely voluntary, confidentiality would be ensured and maintained throughout the study, their names would not be associated with their questionnaire responses, and members of their medical care team would not be informed of whether they chose to participate. Participants were informed that their completed questionnaires would be stored in a secure location and would be destroyed upon completion of the study. Participants were also informed that this study had been approved by the Human Investigations Committee (reference number 07.206) and received contact information for this ethics committee before taking part in the study. Information about the purpose and procedure of the study was discussed and any questions were answered. After reviewing the information letter, participants and

their parents chose whether they wanted to participate; those who wished to participate completed the consent form.

Before completing questionnaires, adolescents were screened for their ability to use a rating scale. They were asked to identify a point on a 7-point Likert scale that represented the amount of like, dislike, or indifference they felt toward an object or event of their choosing (e.g. cheerleading, math homework, going to the dentist, etc.). The scale was represented using numbers, and circles of increasing diameter were used to represent corresponding points of the scale. If they were able to demonstrate appropriate use of this rating scale (e.g., choosing a "7" to indicate the item they liked and choosing a "1" to indicate the item they disliked), adolescents continued in the study and completed the questionnaires.

Parent and adolescent pairs were given questionnaires with corresponding numeric codes so that no identifying marks were needed, but their responses could be compared during data analysis. Instructions on how to complete the questionnaires were given to adolescents and their parents before they completed the questionnaires. Parents completed their questionnaires independently; adolescents completed their questionnaires with the researcher by indicating their response to the questionnaire items read aloud. Parents and their children completed their questionnaires simultaneously, yet independently from each other.

Adolescents completed the GYV-20 (Satisfaction) and the GYV-20 (Importance). Parents completed the MPOC-20 (Satisfaction) and the MPOC-20 (Importance). The order of presentation and completion of questionnaires was counterbalanced. The "More About You" questionnaire was completed last by both adolescents and their parents so

that responses to this questionnaire did not influence participants' responses to other questionnaires. All questionnaires were collected by the researcher upon completion.

Data Analysis

Data from the questionnaires were analyzed using the SPSS program. Estimates of internal consistency for the subscales of the GYV-20 and the MPOC-20 were determined using Cronbach's alpha. Relationships between subscale items were analyzed using Pearson product-moment correlations and factor analysis.

Scores from the MPOC-20 were combined to give a composite score for each of its five subscales (enabling and partnership, providing general information, providing specific information, coordinated and comprehensive care, and respectful and supportive care). Scores from the GYV-20 were combined to give a composite score for each of its four subscales (supportive and respectful relationships, information sharing and communication, supporting independence, and teen centered service). A higher score indicated a higher degree of satisfaction or importance regarding each domain of health care.

To answer the first research question (To what extent are adolescents satisfied with the health care they receive?) mean scores from the GYV-20 (Satisfaction) and its four subscales were assessed (range 1.00 – 7.00). A higher mean indicated a higher degree of satisfaction with the health care received by adolescents with physical disabilities. Mean scores from the MPOC-20 (Satisfaction) and its five subscales were also assessed (range 1.00 – 7.00) to determine parental satisfaction with the health care their child received; a higher score indicated a higher degree of satisfaction. Within-

subjects analyses of variance were conducted with both adolescent and parent data sets to determine whether participants were more satisfied with some aspects of care than others. Finally, Pearson product-moment correlations and mixed design analyses of variance were conducted with both adolescent and parent data sets to determine whether there were differences in satisfaction among participants from different demographic groups.

To answer the second research question (Which aspects of care do adolescents identify as important to their satisfaction with care?), mean scores (range 1.00 – 7.00) from each subscale of the GYV-20 (Importance) were assessed. A higher mean indicated a domain that adolescents identified as more important to their health care. Mean scores (range 1.00 – 7.00) for each domain of the MPOC-20 (Importance) were also calculated to determine which aspects of care parents identified as important to the health care their child receives. Within-subjects analyses of variance were conducted with both adolescent and parent data sets to determine whether there were differences among aspects of care important to adolescents and to parents. Finally, Pearson product-moment correlations and mixed design analyses of variance were conducted to determine whether there were differences regarding important aspects of care among adolescents and parents from different demographic groups.

To answer the third research question (How similar are adolescent perceptions to those of their parents?), descriptive statistics were also employed. Although the MPOC-20 and the GYV-20 assessed similar domains of satisfaction with health care, these two questionnaires could not be directly compared using traditional statistical tests (e.g. t-tests). Therefore, overall means and subscale means from the MPOC-20 and the GYV-20 were computed and examined.

To answer the fourth research question (Do adolescent perceptions of care relate to their intentions to comply with treatment plans?) regression analysis was used to analyze responses to the GYV-20 as predictors of responses to the "More About You" questionnaire item regarding adolescents' intentions to adhere to treatment plans. Finally, demographic variables of age, gender, place of residence, diagnosis, and perceived severity of condition were explored as predictors of satisfaction using regression analysis.

RESULTS

The following sections describe the information obtained from the adolescent questionnaires (GYV-20 Satisfaction and GYV-20 Importance) and parent questionnaires (MPOC-20 Satisfaction and MPOC-20 Importance). Data from adolescents and parents for each questionnaire item are reported in Appendix B. Firstly, findings concerning ratings of satisfaction and importance are reported for adolescent and parent questionnaire items overall, as well as for the questionnaire subscales. Secondly, findings from a more detailed analysis of the measures are reported, including further exploration of the measures' reliability, subscales' inter-item relationships, and additional subscale analyses. Finally, findings from qualitative, open-ended questions are reported describing aspects of care that adolescents and their parents both liked and would like to change.

Are adolescents satisfied with the health care services they receive?

Tests of internal consistency of the GYV-20 (Satisfaction) were computed using Cronbach's alpha. Overall, the measure demonstrated high reliability as $\alpha = 0.88$. Reliability for some individual subscales was somewhat lower ($\alpha = 0.57 – 0.88$), but was determined to be acceptable given the low number of participants ($n = 21$) and the number of question items for each subscale (5 items each). Reliability statistics for all questionnaire items and for questionnaire subscales are presented in Table 2.

Table 2

Reliability Statistics (Cronbach's alpha) for the GYV-20 Measure

Subscale	# Items	Satisfaction	Importance
All Questionnaire Items	20	.88	.92
Supportive and Respectful Relationships	5	.88	.67
Information Sharing and Communication	5	.57	.77
Supporting Independence	5	.66	.82
Teen Centered Services	5	.64	.56

After completing tests of internal consistency, Pearson product-moment correlations were computed to determine the relationships between subscale items. Correlation matrices for subscale items are presented in Appendix E. These findings will be discussed in more detail in subsequent sections as they pertain to the development of the GYV-20 (Satisfaction) measure.

According to the GYV-20 (Satisfaction), using all 20 questionnaire items, adolescents with physical disabilities reported that they were very satisfied overall with the health care services they received. The mean score was 6.59 (sd = 0.48) out of a possible score of 7. Adolescents also reported that they were satisfied with all domains of health care assessed by subscales of the GYV-20 (Satisfaction) including supportive and respectful relationships, information sharing and communication, supporting independence, and teen centered services. Mean scores and standard deviations for subscales are presented in Table 3.

Table 3

Means and Standard Deviations for Subscales of the GYV-20 Measure

Subscale	Satisfaction	Importance
Supportive and Respectful Relationships	6.57 (0.55)	6.61 (0.53)
Information Sharing and Communication	6.61 (0.49)	6.81 (0.37)
Supporting Independence	6.54 (0.54)	6.58 (0.53)
Teen Centered Services	6.63 (0.47)	6.78 (0.29)

Adolescents did not report that they were any more satisfied with certain aspects of care than others. Using within-subjects ANOVA, means for subscales were compared and no significant differences were identified among aspects of care with which adolescents were satisfied ($F(3) = 0.86$, $p = 0.47$); the ANOVA summary table is presented in Appendix C, Table C1. Adolescents reported similar ratings of satisfaction among the four domains of care assessed.

Data were analyzed to determine whether adolescents' satisfaction with health care services was related to demographic variables. Pearson product-moment correlations indicated that adolescent age was not related to overall satisfaction ($r = -.19$, $p = 0.40$), nor was it related to satisfaction ratings of subscales: information sharing and communication ($r = -.17$, $p = 0.47$), supportive and respectful relationships ($r = -.20$, $p = 0.39$), supporting independence ($r = -.25$, $p = 0.29$), and teen centered services ($r = -.11$, $p = 0.65$). Severity of adolescents' condition was not related to their overall satisfaction with health care services ($r = -.01$, $p = 0.96$) and it was not related to their satisfaction

with information sharing and communication (r = -.02, p = 0.92), supportive and respectful relationships (r = .03, p = 0.91), supporting independence (r = -.04, p = 0.87), or teen centered services (r = -.01, p = 0.98) aspects of the health care experience.

Three mixed-design analyses of variance were conducted to determine if there were differences in adolescents' ratings of satisfaction among different demographic groups; the means of four GYV-20 (Satisfaction) subscales were entered as the within-subjects variable and the characteristic of either gender, diagnosis, or place of residence was entered as the between-subjects variable. ANOVA summary tables are presented in Appendix C, Tables C2 – C4. Results indicated that there were no main effect differences in adolescents' ratings of satisfaction according to gender ($F(1) = 0.60$, p = 0.45), diagnosed condition ($F(2) = 0.82$, p = 0.46), or place of residence ($F(2) = 3.17$, p = 0.07). However, there was an interaction between adolescents' ratings of satisfaction and their place of residence ($F(6, 54) = 2.74$, p = 0.02); adolescents from St. John's and rural communities were more satisfied with supportive and respectful relationships and with supporting independence aspects of care than were adolescents from Corner Brook. This interaction is depicted in Figure 4.

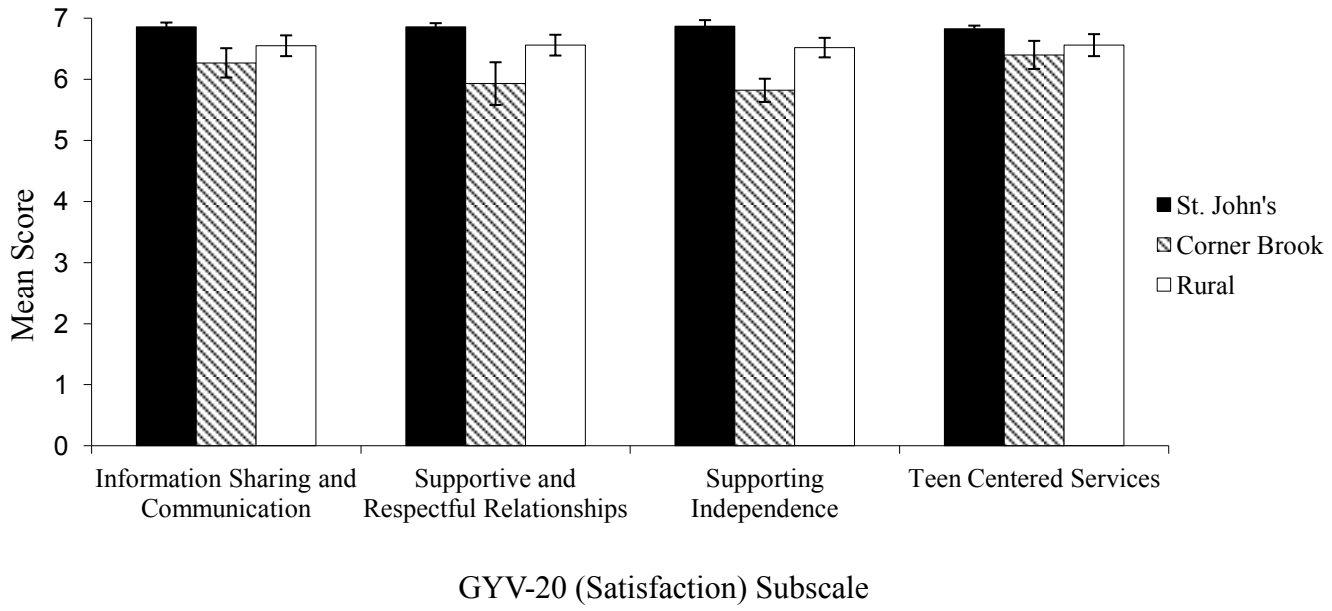

Figure 4. Adolescent reports of satisfaction according to place of residence.

What domains of health care are important to adolescents?

Tests of internal consistency for the GYV-20 (Importance) and its subscales are reported in Table 2. Cronbach's alpha for all questionnaire items was high as $\alpha = 0.92$, while reliability for subscales was somewhat lower ($\alpha = 0.56 – 0.82$). Because of the low number of items per each subscale (5 items each) and the number of participants ($n = 21$), these values were deemed acceptable.

Pearson product-moment correlations were computed to determine the relationships between questionnaire items included in each subscale. These values are reported in correlation matrices in Appendix E and are explored further in subsequent sections as they pertain to the development of the GYV-20 (Importance) measure.

Adolescents reported that the areas of health care assessed by the subscales of the GYV-20 (Importance) were important to them. Mean scores and standard deviations for

the subscales are presented in Table 3. Adolescents reported that different areas of care were important to their satisfaction with health services to varying degrees. Using a within-subjects ANOVA, means for subscales were compared and it was found that some areas of care were more important to adolescents than other areas of care ($F(3) = 5.73$, $p = 0.00$); the ANOVA summary table is presented in Appendix C, Table C5. Paired sample t-tests indicated that information-sharing and communication was more important to adolescents than supportive and respectful relationships ($t(20) = 2.28$, $p = 0.03$) and supporting independence ($t(20) = 2.72$, $p = 0.01$). They also reported that teen centered services were more important to them than supportive and respectful relationships ($t(20) = 2.57$, $p = 0.02$) and supporting independence ($t(20) = 3.02$, $p = 0.01$).

Pearson product-moment correlations were conducted and it was determined that adolescent age was not related to how important they rated the information sharing and communication ($r = -.14$, $p = 0.53$), supportive and respectful relationships ($r = -.30$, $p = 0.18$), supporting independence ($r = -.37$, $p = 0.10$), or teen centered services ($r = -.30$, $p = 0.19$) aspects of the health care experience. Adolescents' perceived severity of their condition was also not related to importance ratings of information sharing and communication ($r = .13$, $p = 0.57$), supportive and respectful relationships ($r = .13$, $p = 0.58$), supporting independence ($r = .14$, $p = 0.56$), or teen centered services ($r = .05$, $p = 0.82$).

Three mixed-design analyses of variance were conducted to determine if there were differences in adolescents' ratings of what was important to them among different demographic groups; the means of four GYV-20 (Importance) subscales were entered as the within-subjects variable and the characteristic of either gender, diagnosis, or place of

residence was entered as the between-subjects variable. ANOVA summary tables are presented in Appendix C, Tables C6 – C8. Results indicated that there were no main effect differences in adolescents' ratings of importance according to gender ($F(1) = 0.10$, $p = 0.76$), diagnosed condition ($F(2) = 0.61$, $p = 0.56$), or place of residence ($F(2) = 0.02$, $p = 0.98$).

Are parents of adolescents with physical disabilities satisfied with health care services?

Tests of internal consistency of the MPOC-20 (Satisfaction) were computed using Cronbach's alpha. Overall, the measure demonstrated high reliability as $\alpha = 0.86$; the reliability for subscales was also high ($\alpha = 0.84 – 0.93$). Reliability statistics for all questionnaire items and for questionnaire subscales are presented in Table 4.

Table 4

Reliability Statistics (Cronbach's alpha) for the MPOC-20 Measure

Subscale	# Items	Satisfaction	Importance
All Questionnaire Items	20	.86	.89
Respectful and Supportive Care	5	.89	.54
Providing General Information	5	.90	.85
Providing Specific Information	3	.84	.57
Coordinated and Comprehensive Care	4	.91	.55
Enabling and Partnership	3	.93	.37

Pearson product-moment correlations were used to determine the relationships between questionnaire items included on each of the five subscales. These correlation matrices are reported in Appendix E and are discussed in more detail later.

Similar to their children, parents reported that they were satisfied with the health care services their child received at the provincial health centre. Parents reported a mean score of 6.31 (*sd* = 0.87) out of a possible score of 7 for overall satisfaction.

Parents reported that they were satisfied with all domains of care assessed by the subscales of the MPOC-20 (Satisfaction); means and standard deviations are presented in Table 5. Parents were satisfied with respectful and supportive care, providing general information, providing specific information, coordinated and comprehensive care, and enabling and partnership aspects of the health care experience.

Table 5

Means and Standard Deviations for Subscales of the MPOC-20 Measure

Subscale	Satisfaction	Importance
Respectful and Supportive Care	6.62 (0.69)	6.74 (0.31)
Providing General Information	6.04 (1.23)	6.37 (0.75)
Providing Specific Information	5.93 (1.27)	6.51 (0.58)
Coordinated and Comprehensive Care	6.52 (0.86)	6.87 (0.22)
Enabling and Partnership	6.38 (0.98)	6.71 (0.35)

A within-subjects ANOVA indicated that parents were more satisfied with some aspects of care than with others ($F(4) = 6.56$, $p = 0.00$); the ANOVA summary table is presented in Appendix C, Table C9. Using paired samples t-tests, it was determined that parents were more satisfied with respectful and supportive care than with the enabling and partnership ($t(20) = 2.59$, $p = 0.02$), receiving general information ($t(19) = 3.54$, $p = 0.00$), and receiving specific information ($t(20) = 3.32$, $p = 0.00$) aspects of care. Parents also identified that they were more satisfied with coordinated and comprehensive care and with enabling and partnership domains of care than with the general information ($t(19) = 2.97$, $p = 0.01$ and $t(19) = 2.26$, $p = 0.02$, respectively) and the specific information ($t(20) = 2.90$, $p = 0.01$ and $t(20) = 2.08$, $p = 0.05$, respectively) provided regarding their child's condition.

Pearson product-moment correlations were computed to determine the relationships between parents' satisfaction with health care services and adolescents' age and severity of their condition. Adolescent age was not related to overall parent satisfaction ($r = .35$, $p = 0.12$), nor to any aspects of care assessed by subscales: respectful and supportive care ($r = .32$, $p = 0.16$), providing general information ($r = -.29$, $p = 0.21$), providing specific information ($r = .38$, $p = 0.09$), coordinated and comprehensive care ($r = .42$, $p = 0.06$), or enabling and partnership ($r = .16$, $p = 0.49$). Parent overall satisfaction was not related to adolescents' ratings of the perceived severity of their condition ($r = -.16$, $p = 0.49$), nor to any aspects of care assessed by the subscales of respectful and supportive care ($r = -.22$, $p = 0.35$), providing general information ($r = -.08$, $p = 0.73$), providing specific information ($r = .11$, $p = 0.64$), coordinated and comprehensive care ($r = -.24$, $p = 0.30$), or enabling and partnership ($r = -.33$, $p = 0.14$).

Three mixed-design analyses of variance were conducted to determine if there were differences in parents' ratings of satisfaction among different adolescent demographic groups. The means of the five MPOC-20 (Satisfaction) subscales were entered as the within-subjects variable and the adolescent characteristic of either gender, diagnosis, or place of residence was entered as the between-subjects variable. ANOVA summary tables are presented in Appendix C, Tables C10 – C12. Results indicated that there were no main effect differences in parents' ratings of satisfaction according to adolescent gender ($F(1) = 1.86$, $p = 0.19$) or place of residence ($F(2) = 2.13$, $p = 0.15$). However, there was a main effect difference between parents' ratings of satisfaction and diagnosis of their adolescent ($F(2) = 3.93$, $p = 0.04$). Independent samples t-tests indicated that parents of adolescents diagnosed with cerebral palsy and parents of adolescents diagnosed with spina bifida were more satisfied than parents of adolescents diagnosed with other conditions, specifically regarding subscales of providing general information ($t(10) = 2.87$, $p = 0.02$ and $t(9) = 2.27$, $p = 0.05$, respectively) and enabling and partnership ($t(11) = 2.29$, $p = 0.04$ and $t(9) = 2.50$, $p = 0.03$, respectively). These results are depicted in Figure 5.

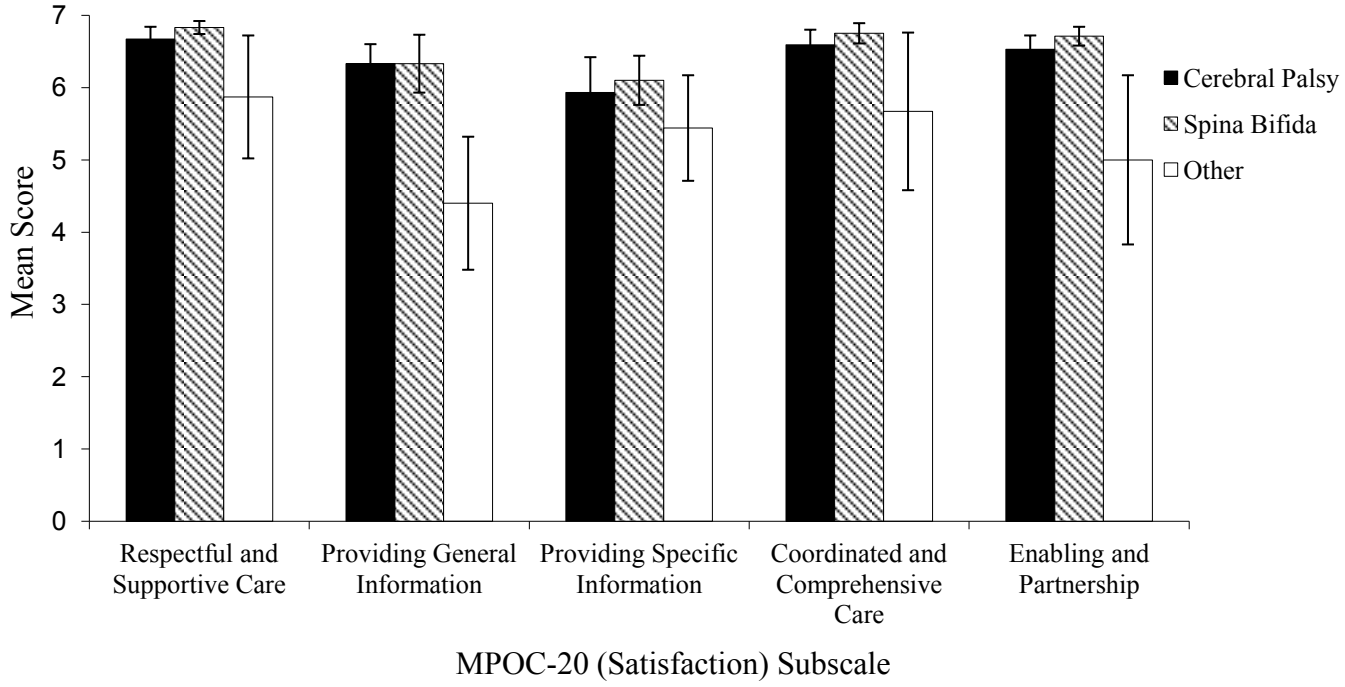

Figure 5. Parent reports of satisfaction according to adolescent diagnosis.

What domains of care are important to parents of adolescents with physical disabilities?

Tests of internal consistency for the MPOC-20 (Importance) and its subscales are reported in Table 4. Cronbach's alpha for all questionnaire items was high as $\alpha = 0.89$ while reliability for subscales was lower ($\alpha = 0.37 – 0.85$). These values were determined to be acceptable due to the low number of questions included in each subscale (3, 4, or 5 items) and the number of participants ($n = 21$).

Pearson product-moment correlations were completed to investigate the relationships between questionnaire items included in each subscale. These correlation matrices are presented in Appendix E and are discussed in more detail later as they pertain to the development of the MPOC-20 (Importance) measure.

Parents indicated that all domains of health care assessed were important to them. Means and standard deviations for the subscales of the MPOC-20 (Importance) are presented in Table 5.

Parents reported that certain aspects of care were more important to them than others as indicated using a within-subjects ANOVA ($F(4) = 5.99$, $p = 0.00$); this ANOVA summary table is presented in Appendix C, Table C13. Paired samples t-tests indicated that coordinated and comprehensive care for their child was more important to them than all other aspects of care: respectful and supportive care ($t(20) = 2.46$, $p = 0.02$), enabling and partnership ($t(20 = 2.06$, $p = 0.05$), providing general information ($t(19) = 3.62$, $p = 0.00$), and providing specific information ($t(20) = 3.12$, $p = 0.01$). Parents also reported that respectful and supportive care was more important to them than receiving general information ($t(19) = 3.00$, $p = 0.01$) or specific information ($t(20) = 2.27$, $p = 0.04$) about their child's condition; enabling and partnership was also more important than the general information provided ($t(19) = 2.18$, $p = 0.04$).

Pearson product-moment correlations were used to determine the relationships between aspects of care that were important to parents and adolescents' age and severity of their condition. Adolescent age was not significantly related to parent ratings of the importance of respectful and supportive care ($r = -.08$, $p = 0.72$), providing general information ($r = -.01$, $p = 0.98$), providing specific information ($r = -.05$, $p = 0.85$), coordinated and comprehensive care ($r = -.02$, $p = 0.93$), or enabling and partnership ($r = -.20$, $p = 0.39$). Adolescents' ratings of the perceived severity of their condition were not related to parents' ratings of the importance of respectful and supportive care ($r = -.19$, $p = 0.41$), providing general information ($r = -.15$, $p = 0.54$), providing specific information

(r = .03, p = 0.91), or coordinated and comprehensive care (r = -.41, p = 0.07). Adolescents' reports of the perceived severity of their condition was inversely related to parents' ratings of the importance of enabling and partnership (r = -.43, p = 0.05); adolescents reporting more serious conditions had parents rating enabling and partnership with the health care provider as less important to them.

Three mixed-design analyses of variance were conducted to determine if there were differences in parents' ratings of importance among different adolescent demographic groups; the means of five MPOC-20 (Importance) subscales were entered as the within-subjects variable and the adolescent characteristic of either gender, diagnosis, or place of residence was entered as the between-subjects variable. These ANOVA summary tables are presented in Appendix C, Tables C14 – C16. Results indicated that there were no main effect differences in parents' ratings of what was important to them according to adolescent gender ($F(1) = 1.35$, $p = 0.26$) or place of residence ($F(2) = 0.62$, $p = 0.55$). However, there was a main effect difference between parents' ratings of importance and diagnosis of their adolescent ($F(2) = 3.79$, $p = 0.04$). Independent samples t-tests indicated that coordinated and comprehensive care and enabling and partnership aspects of care were more important to parents of adolescents diagnosed with cerebral palsy ($t(11) = 5.62$, $p = 0.00$ and $t(11) = 2.41$, $p = 0.04$, respectively) and to parents of adolescents diagnosed with spina bifida ($t(9) = 2.71$, $p = 0.02$ and $t(9) = 4.07$, $p = 0.00$, respectively) than to parents of adolescents diagnosed with other conditions. Parents of adolescents diagnosed with cerebral palsy also rated respectful and supportive care ($t(11)$ = 2,42, $p = 0.03$) and providing general information ($t(10) = 2.45$, $p = 0.04$) as more

important than did parents of adolescents diagnosed with other conditions. These results are depicted in Figure 6.

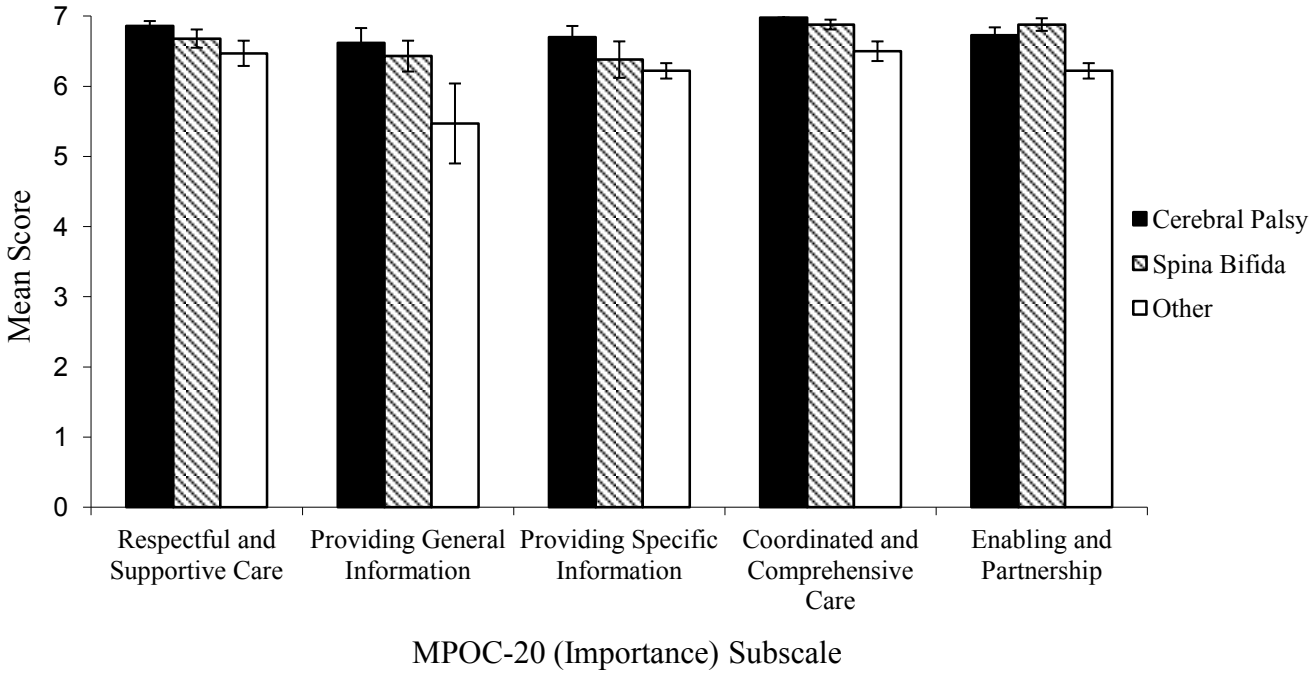

Figure 6. Parent reports of importance of aspects of care according to adolescent diagnosis.

How similar are adolescents' and parents' perceptions of the health care experience?

Because the adolescent and the parent questionnaires differ, it is not possible to directly compare responses to these questionnaires using conventional statistical analyses. To compare perspectives from both groups it is only possible to discuss the findings from adolescents and their parents, describe patterns of responses within each group, and then draw conclusions about their similar or differing perspectives regarding satisfaction with health care services.

Regarding overall satisfaction with health care services, adolescents reported a mean score of 6.59 (*sd* = 0.48) of a possible score of 7, and parents reported a mean score of 6.31 (*sd* = 0.87) of a possible score of 7. Even though adolescents reported a higher satisfaction score, both adolescent and parent scores are very high and have very little variability. Therefore, it can be inferred that adolescents and their parents reported similar perspectives regarding satisfaction with the health care services they received. Both adolescents and their parents reported that they were overall very satisfied with health care services.

Adolescents and their parents reported being satisfied with specific aspects of health care services also. When describing satisfaction with their relationships with health care providers, adolescents reported a mean score of 6.57 (*sd* = 0.55) for the GYV-20 (Satisfaction) subscale of supportive and respectful relationships, and parents reported a mean score of 6.62 (*sd* = 0.69) for the MPOC-20 (Satisfaction) subscale of respectful and supportive care. Although these means cannot be compared using traditional statistical tests, it appears as though adolescents and parents reported similar high ratings of satisfaction with the respect and support experienced within the client-health care provider relationship.

Communication about condition information and progress toward treatment goals was another aspect of care that was assessed by both adolescent and parent questionnaires (information sharing and communication and providing general/specific information subscales, respectively). Adolescents reported that they were satisfied with the information-sharing and communication aspect of health care (mean = 6.61, *sd* = 0.49) and parents reported satisfaction with the amount of general information (mean = 6.04, *sd*

= 1.23) and the amount of specific information (mean = 5.93, *sd* = 1.27) provided to them about their child's condition and progress. Adolescents and their parents both reported high ratings of satisfaction with this aspect of health care and had very little variability in their responses. Again, these means cannot be compared using traditional statistical tests, but it appears as though adolescents and their parents reported similar perspectives regarding their satisfaction with the communication of information.

The other subscales of the GYV-20 (teen centered services and supporting independence) and of the MPOC-20 (coordinated and comprehensive care and enabling and partnership) assessed different aspects of care from the adolescent and the parent perspectives. Therefore, means from these subscales were not explored to compare adolescent and parent perceptions.

How similar are adolescents' and parents' perceptions of what's important to them?

It was also interesting to explore similarities between adolescents and parents regarding which aspects of care were important to them. Regarding the importance of supportive and respectful relationships, adolescents reported a mean of 6.61 (*sd* = 0.53) for this subscale of the GYV-20 (Importance) and parents reported a mean of 6.75 (*sd* = 0.31) for this subscale of the MPOC-20 (Importance). Upon visual comparison of these means, feeling respected and supported by the health care provider was very important to both adolescents and their parents.

When analyzing adolescent and parent perspectives regarding sharing of information, adolescents reported a mean of 6.81 (*sd* = 0.37) for this subscale of the GYV-20 (Importance) and parents reported a mean of 6.37 (*sd* = 0.75) for providing

general information and a mean of 6.51 (*sd* = 0.58) for providing specific information subscales of the MPOC-20 (Importance). From these reports, it appears as though receiving information about their condition, treatment, and progress was very important both to adolescents and to their parents.

The remaining subscales from adolescent and parent questionnaires were not analyzed as they assessed different aspects of care from the adolescent and parent point of view.

Are adolescent ratings of satisfaction related to their parents' ratings of satisfaction?

It was not possible to directly compare adolescent and parent reports of satisfaction using t-tests, but it was possible investigate whether their reports of satisfaction were correlated (i.e., were adolescents reporting high satisfaction likely to have parents reporting high satisfaction?) using Pearson product-moment correlations. Results indicated that there was no significant relationship between adolescent and parent reports of satisfaction (r (21) = -0.15, p = 0.53). Adolescent scores of satisfaction using the GYV-20 (Satisfaction) were not related to their parents' scores of satisfaction using the MPOC-20 (Satisfaction).

Do adolescent perceptions of care relate to their intentions to adhere to treatment plans?

Adolescents were asked whether clinic staff provided them with suggestions for things to do at home (e.g. stretching, exercises); twenty adolescents reported a "yes" response and two adolescents reported a "no" response. Of the two adolescents reporting "no" to this item, one adolescent reported that they were being discharged following this

clinic visit, and one adolescent reported that they had received suggestions at a younger age but no longer received suggestions. Of the twenty adolescents reporting "yes" to this item, 7 adolescents reported that they intended to follow treatment recommendations, 12 adolescents reported that they intended to follow recommendations some of the time, and 1 adolescent reported that he (or she) would not follow treatment recommendations.

Logistic regression analysis was conducted to determine whether adolescents' satisfaction with health care services could predict their reported intentions to adhere to treatment recommendations; adolescent satisfaction was the independent variable and intentions to adhere to treatment suggestions was the dependent variable (n = 19). A test of the full model against a constant-only model was not statistically significant ($\chi^2(1) = 1.48$, $p = 0.22$), indicating that adolescent satisfaction could not reliably distinguish between adolescents who responded "yes" and "sometimes" to this question. The Wald criterion demonstrated that adolescent satisfaction ratings did not make a significant contribution to prediction ($Wald = 1.10$, $p = 0.29$). Prediction success overall was 63.2%. Adolescents' reported intentions to adhere to treatment recommendations could not be reliably predicted from their reported satisfaction with health care services.

Further analysis of the GYV-20 and the MPOC-20 measures

Adolescents' perceptions of their satisfaction with health care services are important, so it is important to develop valid and reliable measures that assess their perspectives. Initial analysis of the results from the GYV-20 (Satisfaction), GYV-20 (Importance), MPOC-20 (Satisfaction), and the MPOC-20 (Importance) evaluated the internal consistency of these measures using Cronbach's alpha. Results indicated that

reliability of these measures overall was high, but reliability of the measures' subscales was somewhat low. Because of the low number of participants and question items included on each subscale, the alpha levels were determined to be acceptable for subsequent data analysis, as indicated above. However, because Cronbach's alpha was valued at $\alpha < 0.70$ for some subscales, it was considered advisable to examine the properties of the measures themselves more closely and to exercise caution when evaluating the results for this participant sample using these measures.

The following section discusses the exploratory analyses of the four measures used in this study. For each of the measures, tests of internal consistency were used to explore reliability, Pearson product-moment correlations were used to explore inter-item relationships, and factor analysis was used to determine potential item groupings based on the responses from this sample of participants. It should be noted that these analyses are exploratory in nature as the low number of participants ($n = 21$) limits the ability to generalize findings to other participant samples. Results from these analyses for each of the four measures are presented below.

Measure of Processes of Care – 20 (Satisfaction)

The MPOC-20 (Satisfaction) was used to determine the extent to which parents of adolescents with physical disabilities are satisfied with health care experiences. For this sample of parents, tests of internal consistency for the measure overall and for the five measure subscales were high, as indicated in Table 4. Cronbach's alpha for this sample on this measure was similar to the sample of participants used for its development and subsequent use (King et al., 2004). The MPOC-20 (Satisfaction) demonstrated good

reliability, and therefore no further exploratory analyses to evaluate this measure were conducted.

Measure of Processes of Care – 20 (Importance)

The MPOC-20 (Importance) was a measure adapted from the MPOC-20 (Satisfaction) for use in this study; it had not been previously developed and its psychometric properties had not been determined. Preliminary analysis of internal consistency using Cronbach's alpha indicated that overall reliability was high, while reliability of the subscales ranged from $\alpha = 0.37$ to 0.85. This wide range of values suggested that a more detailed evaluation of this measure for this sample would be prudent.

Following initial tests of reliability, each of the items included in each of the five measure subscales was evaluated to determine whether it's removal from the subscale would improve the scales' reliability. These values are presented in Appendix D, Table D1. Removal of some subscale items would improve the Cronbach's alpha values of some subscales, but most values would still remain at $\alpha < 0.70$.

Pearson product-moment correlations were conducted to determine the relationship between each subscale item and each other individual item included. These correlation matrices are presented in Appendix E, Tables E1 – E5. These analyses indicated that some questionnaire items were of concern as they showed different patterns of parents' responses.

Finally, factor analysis was conducted to examine whether the five subscales would emerge as factors. The results are indicated in Appendix F, Table F1. The factor analysis did not identify the five subscales defined by the authors of the measure, but

instead indicated questionnaire items should be grouped together differently to better reflect the responses of this participant sample.

Taken together, the results of these statistical analyses suggest that the subscales of the MPOC-20 (Importance) may need to be reconsidered. Particularly, item 9 ("How important is it to you that the people who work with your child provide enough time for you to talk so you don't feel rushed?") and item 10 ("How important is it to you that the people who work with your child plan together so they are all working in the same direction?") were of concern: their removal from the subscales of respectful and supportive care and coordinated and comprehensive care, respectively, would improve the subscales' reliability, as these items were negatively correlated with other items included in the subscales, and these items emerged as a separate factor in the factor analysis. This further exploration into the MPOC-20 (Importance) therefore highlighted some concerns with questionnaire items that should be taken into account when evaluating the results from this measure.

Giving Youth a Voice – 20 (Satisfaction)

The Giving Youth a Voice – 20 (Satisfaction) questionnaire was developed from the Measure of Processes of Care for use with adolescents with chronic health conditions (Gan et al., 2008). This measure was used in this study to investigate the extent to which adolescents with chronic health conditions were satisfied with the health care services they received. Tests of internal consistency using Cronbach's alpha indicated that the reliability for the measure overall was high ($\alpha = 0.88$), while reliability for the four subscales was somewhat lower. Further investigation of the subscales indicated that

reliability could be improved if some items were removed; these values are presented in Appendix D, Table D2.

Following tests of internal consistency, Pearson product-moment correlations were conducted to examine the relationships between all items included on each subscale. These correlation matrices are presented in Appendix E, Tables E6 – E9. It is evident that some subscale items demonstrate stronger relationships than others with other items. Particularly, item 4 ("How much do the people who work with you tell you details of your treatment, such as the reasons for it, what is being done, and for how long?") was not significantly related to other items included on the information sharing and communication subscale, item 17 ("How much do the people who work with you give you a chance to say what you want to get out of treatment?") was not significantly related to other items of the supporting independence subscale, and item 15 ("How much do the people who work with you seem aware that your needs change as you get older?") was not significantly related to any other items of the teen centered services subscale. These weak item relationships suggest that these items are of concern when evaluating the questionnaire subscales.

Finally, factor analysis of questionnaire items was conducted to determine whether author-defined subscales would emerge as factors for this sample. The results are presented in Appendix F, Table F2. The factor analysis did not confirm the four subscales as defined by the authors of the measure, but instead indicated questionnaire items should be grouped together differently to better reflect the responses of this participant sample.

The results of the reliability analysis, Pearson product-moment correlations, and factor analysis indicate that the subscales of the GYV-20 (Satisfaction) may not be well-suited for this sample of adolescent participants. In particular, questionnaire items 4, 15, and 17 are of concern. These three items' removal from their respective subscales would increase the internal consistency of the subscales, these items were not significantly related to other items on their respective subscales, and these items were identified to form an independent factor using the factor analysis. These exploratory analyses therefore suggest some concerns with certain questionnaire items that should be taken into account before future use of this measure.

Giving Youth a Voice – 20 (Importance)

The Giving Youth a Voice – 20 (Importance) measure was adapted from the Giving Youth a Voice – 20 (Satisfaction) for use in this study to investigate which aspects of the health care experience are important to adolescents with chronic health conditions. This measure had not been previously developed and its psychometric properties had not been established. Initial tests of internal consistency using Cronbach's alpha indicated that the measure overall had high reliability, while reliability for some measure subscales was lower. Further exploration indicated that the reliability of the subscales could be improved if some items were removed. These results are presented in Appendix D, Table D3.

Pearson product-moment correlations were conducted to investigate subscale inter-item correlations; these results are presented in Appendix E, Tables E10 – E13. These correlation matrices depict that some questionnaire items are of concern as they have weak or inverse relationships with other items included on the subscale. In particular,

item 20 (“How much do the people who work with you offer you useful information about how you are doing?”) was not strongly related to other items of the supportive and respectful relationships subscale, and item 6 (“How much do the people who work with you treat you as a young adult rather than a child?”) was inversely related to some items included on the teen centered services subscale.

Finally, factor analysis was conducted to explore which subscales would emerge as appropriate for this sample of participants; this information is presented in Appendix F, Table F3. The four subscales as defined by the authors of the measure did not emerge as significant factors, but four other factors were identified as appropriate to explain the responses of participants in this sample.

The results of the reliability analysis, Pearson product-moment correlations, and factor analysis suggest that the subscales of the GYV-20 (Importance) may not be optimized for this sample of adolescents. Specifically, item 6 and item 20 were identified as potential items of concern as response patterns to these items differed from other questionnaire items. These findings should be taken into account prior to future use of this measure.

Other perspectives from adolescents?

In addition to completing quantitative measures about their perspectives regarding their health care, adolescents and their parents were asked two open-ended questions: “Which aspects of care did you like the best?”, and “Which aspects of care would you like to change?”. Responses to these questions from adolescents and their parents are reported in Appendix G. A total of 19 adolescents responded to at least one of these

questions; 3 adolescents did not respond. Nineteen parents also responded to at least one of these qualitative questions; 3 parents did not respond.

When asked what they liked best about the care they received, 17 adolescents gave responses and 5 adolescents did not respond. Adolescents' responses clustered around two themes: staff interpersonal style and staff service delivery style. Adolescents commented about staff personality traits and interpersonal style. They reported that staff members were "friendly", "nice", "helpful", and "easy to get along with". Adolescents also reported feeling a personal connection with staff members; adolescents felt as though they were recognized and familiar, as though staff members knew them and cared about them personally. One adolescent commented, "They're there when you need them, all you have to do is call". Another adolescent commented, "Everyone knows me, I know them". Adolescents reported feeling as though staff members were very supportive and available for them during their treatment process.

Adolescents also commented about service delivery style of staff members. They reported that staff members "help with problems" and "answer questions honestly". Adolescents reported that staff members provided them with information about treatment options, gave them enough time to make treatment decisions, gave enough notice if a treatment plan had to be altered, and told the truth about treatments. Adolescents reported that staff provided information to them in a professional and caring atmosphere.

When asked to comment about areas of care that they would like done differently, 15 adolescents reported that they would not change anything. However, 4 adolescents did report that they would like to change some aspects of the structure of care. The most common change suggested by these adolescents was that they would like clinic wait

times to improve. Adolescents reported that they could arrive for a clinic appointment and spend much time waiting to be seen by several professionals, resulting in several hours missed from school. While the adolescents understood the need for wait times, they suggested that activities be available for them while waiting for their clinic appointment. In addition to wait time, one adolescent commented about the structure of the clinic environment, reporting concern about the confidentiality of her case. She reported that, while she enjoyed the clinic approach, she felt concerned that patients waiting in adjacent exam rooms could overhear clinic staff members discussing her treatment options and outcomes.

Other perspectives from parents?

When asked about which aspects of their child's care they liked the best, 18 parents responded and 4 did not respond. Parents' responses related to two themes: staff interpersonal skills and staff familiarity with their adolescent child. Parents' responses were similar to those of adolescents regarding the interpersonal skills of the staff members. Parents reported they felt as though staff members were very friendly and helpful and showed a genuine interest in them and their adolescent child. One parent reported that staff "make you feel like family… I don't know what we'd do without them." Another parent reported that staff showed interest in their personal life, had genuine concern for them and their child, and made them feel comfortable. Parents commented on the friendliness and caring atmosphere they experienced.

Parents also discussed the familiarity of staff members with their adolescent child. Parents reported they felt as though staff knew them personally and knew their child very well. One parent reported that their adolescent had "been coming here since she was a

baby"; another reported, "they know [adolescent] better than anyone." Parents commented that they felt staff were familiar with their case, and were familiar with them and their child on a personal level.

When asked if there was something they'd like done differently, 14 parents reported that they did not want to change anything and 3 parents did not respond to this question. Five parents reported that there were some changes they would like to see implemented regarding wait times and continuity of care. Parents reported that they would like to see clinic wait times decreased, and one parent suggested that activities be available for the adolescent while waiting for their clinic appointment.

Regarding continuity of care, two parents reported that they would like for information to be more easily available, instead of "following a paper trail." A parent suggested the adolescent have a primary nurse, "a liaison person in the know, instead of always someone different." However, another parent commented that they were "not looking forward to the transition to adult care, as the same personal care won't be there."

DISCUSSION

Are adolescents with chronic physical disabilities satisfied with the health care services they receive?

The adolescents with chronic physical disabilities who participated in this study reported that they were very satisfied with the health care services they received. Responding to the quantitative Giving Youth a Voice (GYV) measure, adolescents reported high ratings of overall satisfaction, with scores that approached the upper limit of possible ratings. Specifically, adolescents reported that they were satisfied with the four domains of care assessed: supportive and respectful relationships, information sharing and communication, supporting independence, and teen centered services. Adolescents reported high ratings of satisfaction with each of these domains of care, as scores approached the upper limit of possible scores. Furthermore, there were no statistically significant differences among adolescents' ratings of satisfaction for these subscales; adolescents reported similar ratings of satisfaction for each of these four areas of care.

The finding that adolescents were satisfied with the health care services they received was further supported by their responses to open-ended questions about their care. When asked about what they liked best about their care, adolescents' comments reflected their satisfaction with their relationship with their service provider and with the information shared with them about their health care. Adolescents reported that service providers showed caring and supportive interpersonal characteristics, such as being "friendly", "helpful", and "easy to get along with"; the supportive and respectful relationships aspect of care is comprised of these traits. Additionally, adolescents

reported that service providers "answered questions honestly" and "helped with problems", characteristics represented by the information sharing and communication aspect of care. And when asked to comment about what they would like done differently, most adolescents reported that they would change nothing about their experience. The few who did suggested structural changes, such as reduced wait times, rather than interpersonal process changes. These results, paired with the results from the quantitative questionnaires, provide strong support for the finding that adolescents are very satisfied with the health care services provided to them.

The current finding that adolescents report high ratings of satisfaction adds weight to previous research findings. For example, both Freed et al. (1998) and Byczkowski et al. (2010) found that adolescents reported high ratings of satisfaction regarding acute health care services they received as outpatients at adolescent health clinics. Similarly, Chesney et al. (2005) found that children and adolescents (aged 4 – 17 years) reported high levels of satisfaction with health care services received at specialty pediatric health clinics. Using various measures of satisfaction, including the GYV measure, Mah et al. (2006) found that the majority of adolescents receiving neurological health care services reported that they were satisfied with overall services they received. It would seem, therefore, that adolescents with both acute and chronic conditions generally report being very satisfied with the health care services they experience.

The adolescents in this study also reported being satisfied with all four interpersonal aspects of care assessed, and they were not more satisfied with one area of care than another. This finding is somewhat unexpected and interesting given the adolescents' responses to the open-ended questions and the findings of a previous study.

Although adolescents did not explicitly state being more satisfied with different areas of care, their comments focused on the patient-provider relationship and the communication of information, supporting an inference that these were particularly salient components of their satisfaction with care. In a previous study using the GYV measure, adolescents reported higher levels of satisfaction for the information sharing and communication subscale and for the teen centered services subscale than for the supportive and respectful relationships and supporting independence subscales (Mah et al., 2006). Because adolescents from the previous and current studies were sampled from two different medical care centers, it is likely that these different findings are related to differences in experiences with personnel, philosophies, practices, and services at the two centers. Despite this dissimilarity in results, it is important to note that adolescents in both health centers reported high ratings of satisfaction with all areas of care assessed.

Adolescents' ratings of satisfaction were not related to demographic characteristics of age, nor gender, nor diagnosed condition, nor perceived severity of their condition, similar to the findings of previous studies (e.g., Mah et al., 2006; Shaw et al., 2006). However, place of residence was related to reported satisfaction, with adolescents from St. John's and rural communities reporting higher satisfaction with supportive and respectful relationships and with supporting independence than adolescents from Corner Brook. The relationship between place of residence and adolescent satisfaction had not been previously investigated and it was a surprising finding given that other demographic variables have not been related to ratings of satisfaction (e.g. Mah et al., 2006; Shaw et al., 2006). As Corner Brook is an urban center, residents would be familiar with accessing services close by with minimal travel. However, adolescents residing in

Corner Brook would need to travel a significant distance to attend appointments at the pediatric health center, thus limiting their contact with and access to health care professionals at the center, and possibly their perceptions of their patient-provider relationship. Although adolescents residing in rural communities would also be required to travel to attend appointments, travel to access services could be expected by this sample, as fewer amenities would be available to them in their community. Due to the small sample of participants residing in Corner Brook, further study would be necessary to investigate the relationship between satisfaction with health care services and place of residence.

Which aspects of care do adolescents identify as important to their satisfaction?

Adolescent participants in this study reported that all aspects of health care assessed by the GYV measure (information sharing and communication, supportive and respectful relationships, supporting independence, and teen centered services) were important to their satisfaction with the care they received. Areas of care adolescents identified as important were not related to demographic characteristics of age, gender, place of residence, diagnosed condition, or perceived severity of their condition.

While adolescents reported that all of these aspects of health care were important to them, certain aspects of care were identified as more important to them than others. Adolescents indicated that information sharing and communication were most important to them, more so than a supportive and respectful relationship or supporting independence. It was important to adolescents that health care providers discuss details regarding the purpose, process, and duration of treatments, inform them about how

treatments may harm or benefit them, explain what they're doing, talk to them honestly, and answer their questions. Adolescents reported that having information communicated to them about the progress of their condition and their treatment options was more important to them than the other relational aspects of the patient-provider relationship assessed, such as showing an understanding of their feelings and helping them feel more sure of themselves.

Adolescents also noted communication of information to them in response to the open-ended question about which areas of care they liked best. Adolescents commented that they liked it when health care professionals provided information about their progress and treatment options, gave them enough time to make treatment decisions, and told the truth about treatments. While this question did not ask about importance, the fact that adolescents responded along this theme supports the inference that receiving information about their care is important to them.

Communication has been a recurring theme in discussions of adolescent health care. For example, based on their finding that adolescents reported a desire to have open and direct communication with their health care provider about their medical tests and procedures, Garth and Aroni (2003) emphasized that it is important to adolescents to be involved in discussions about their care and to be informed participants in the medical consultation. They defined informed participation as adolescents having direct communication with their doctor and being able to answer and ask questions themselves pertaining to their condition and treatment.

Similarly, Byczkowski et al. (2010) found that communication was identified as integral to adolescents' satisfaction with their health care experience. When asked about

what health care providers did to make the medical visit a 'good one', the most common response from adolescents pertained to communication. Specifically, adolescents' identified their preference for medical encounters in which their health care provider told them what to expect during the medical visit regarding tests and procedures, used understandable language, provided them with medical information about their condition and/or treatment, listened to what they had to say, asked them questions about their condition, and answered their questions (Byczkowski et al., 2010).

Although these previous studies did not set out to investigate which aspects of care were important to adolescents, they indicated that communication is a necessary component of adolescents' satisfaction. Adolescents identified that they wanted open communication with their health care provider specifically about their health condition, medical procedures, and treatments (Byczkowski et al., 2010;Garth & Aroni, 2003). This inference is supported by the findings of the current study. Adolescents reported that that their provider's ability to communicate about their medical condition is more important than their ability to convey an understanding of their feelings or to make them feel independent in their health care decisions. It was important for adolescents not only to have friendly conversation during their medical visit, but also to participate in medical discussions.

In addition to communication, adolescents reported that teen centered services were important to them, more so than supportive and respectful relationships and supporting independence. Specifically, adolescents indicated the importance of health care providers treating them as a young adult rather than a child, being aware that their needs change as they get older, getting along well with youth, and treating them as an

individual rather than as a youth with a disability. Adolescents indicated the importance of health care providers recognizing their developmental changes and their individual needs and personalities, and that this aspect of care was more important to them than other aspects.

Interestingly, adolescents did not address developmental considerations in their responses to qualitative questions posed. Adolescents predominantly reported about the communication of information and about the interpersonal aspects of their relationship with their health care provider, and did not comment specifically about teen centered service provision. Some adolescents did comment that providers were "easy to get along with" and "knew" them, akin to portions of the teen centered services subscale. However, developmental changes and needs was not a primary area of care discussed, even though adolescents indicated its importance to them using quantitative measures.

Recognizing their developmental needs was a theme reported by adolescents discussing their perceptions of outpatient care (Byczkowski et al., 2010). In that study, developmental considerations referred to the health care provider speaking to the adolescent appropriately for their age, rather than as a child. Although adolescents in that study did report this as an aspect of care that went well, other studies sampling adolescents with chronic conditions identified that developmental considerations was an area of care that could be improved upon (Mah et al., 2006; van Staa et al., 2011). And although information about the aspects of care that were important to adolescents was not directly investigated in these previous studies, the fact that they brought it up in response to open ended questions about their care indicates that it is an important factor to their satisfaction.

Information regarding areas of care adolescents identify as important to them provides further insight into adolescents' perspectives about their health care experience. Studies seeking to understand what factors are important to satisfaction have often analyzed data in hindsight and have focused on variables such as adolescent demographics, family demographics, health care provider characteristics, or health care facilities as determinants of satisfaction with care; overall, these variables have not been consistently found to be related to satisfaction with care (Mah et al., 2006; Shaw et al., 2006). The current study directly asked adolescents the extent to which these areas of care were important to them. Adolescents indicated that the interpersonal aspects of care assessed are all very important to them, with open and honest communication about their condition and consideration for their developmental needs deemed the most important aspects of their interactions with their health care provider.

Are parents of adolescents with physical disabilities satisfied with health care services?

Parents of adolescents with chronic physical disabilities who participated in this study indicated that they were satisfied overall with the health care services their child received. Responding to the MPOC measure, parents reported high ratings of overall satisfaction, with scores that approached the upper limit of possible ratings. Parents also indicated that they were satisfied with all aspects of care assessed, including respectful and supportive care, providing general information, providing specific information, coordinated and comprehensive care, and enabling and partnership.

While parents reported high satisfaction with these domains of the health care experience, results indicated that parents were more satisfied with some aspects of care

than with others. Specifically, parents were more satisfied with respectful and supportive care, coordinated and comprehensive care, and enabling and partnership aspects of care than with providing general or specific information about their child's condition. Parents were also more satisfied with respectful and supportive care than with the enabling and partnership aspect of care.

Parents reported that they were most satisfied regarding their relationship with their child's health care provider. Parents indicated that they were more satisfied with providers' abilities to foster a caring atmosphere, treat them as an individual and as an equal, and provide enough time for them to contribute to the medical encounter than with the written and oral information provided regarding their child's condition, progress, and assessment results, community services, and treatment decision-making opportunities. Parents were also satisfied with the coordination and comprehensiveness of the care provided to their child; they indicated that providers considered all aspects of their child's needs (including physical, emotional, social, and mental needs), collaborated with each other, and provided consistent information and care. Parents reported being very satisfied with these aspects of the parent-provider relationship, which are integral components of family-centered care service delivery.

Parents were asked to respond to an open-ended question regarding which area of their child's care they liked best. Most parents responded to this question and indicated their satisfaction with the caring and supportive parent-provider relationship and with providers' familiarity with their child's case. Parents commented that health care providers were very friendly and showed a genuine interest in them and their child. These components of care were similar to the respectful and supportive care scale

assessed by the quantitative questionnaire, and offer further evidence that parents were very satisfied with the family-centered nature of their relationship with their child's health care provider.

Previous studies have also found parents to be satisfied with their experience during the medical encounter, especially regarding their relationship with their child's health care provider. Parents whose children received acute care and outpatient care have reported high ratings of overall satisfaction with services (Byczkowski et al., 2010; Davis, 1995; Petersen et al., 2006). Parents of adolescents with special health care needs have also indicated being satisfied with their child's health care, especially regarding their interactions with clinic staff and their communication with health care providers (Wood et al., 2009). Dyke, Buttigieg, Blackmore, and Ghose (2006) found that parents of children with physical disabilities were more satisfied with relational aspects than with informational aspects of the health care experience. Using the MPOC-56, parents reported that they were most satisfied with respectful and supportive care and least satisfied with the general information provided to them (Dyke et al., 2006). In another study, the majority of parents reported being satisfied with their communication with their child's health care provider and involvement in decision-making, but dissatisfied with providers' abilities to connect them with community resources (Wood et al., 2009). Parents have indicated being satisfied with the parent-provider relationship when they have felt as though the provider treated them with respect and dignity (Byzckowksi et al., 2010), cared for them, showed interest in them, and collaborated with them about treatment decisions (Galil et al., 2006).

The relationship between parent satisfaction with care and adolescent characteristics was investigated. Previous research has indicated that parents of younger adolescents or adolescents with less severe conditions are more satisfied with services (Knapp et al., 2010; Summers et al., 2005) but the current study did not find a relationship between adolescent age, severity of their condition, gender, or place of residence. However, there were differences in parent ratings of satisfaction depending on adolescent diagnosis. Parents of adolescents diagnosed with either cerebral palsy or spina bifida were more satisfied with the enabling and partnership and the general information domains of care than parents of adolescents diagnosed with other conditions.

The enabling and partnership domain refers to parents' ability to choose the type and timing of the information they desire, be enabled to fully understand treatment choices, and make decisions about their child's treatment. The providing general information domain refers to parents' receipt of general information about their child's condition, the availability of information in various forms (e.g., videos, books, kits), and information about community support services available. Health care provider communication about condition information is a theme within these domains of care. It is possible that there is not much information available about conditions classified as "other", and this would affect the health care provider's ability to provide information to parents about treatment choices and community supports. Reduced information could be related to reduced parent-provider communication and parental involvement during the clinic visit, and thus decreased satisfaction with these areas of care (Galil et al., 2006). It is important to note that parents were comparably satisfied with other interpersonal

aspects of care, thus supporting the theory that availability of information about other conditions was a factor in decreased satisfaction for parents of this adolescent group.

Another possible reason for the differences in parent satisfaction ratings among diagnostic groups includes confounding variables. Adolescent age, condition severity, and maternal stress have been related to parental satisfaction (Knapp et al., 2010; Mitchell & Hauser-Cram, 2008; Summers et al., 2005). It is possible that the adolescents sampled with conditions other than cerebral palsy or spina bifida were older, had more severe conditions, or had parents experiencing more stress, thus yielding lower parental satisfaction ratings for these two domains of care. It is also noteworthy that there were few adolescents reporting conditions other than cerebral palsy or spina bifida, which may have influenced the statistical reliability of parental satisfaction scores. Further investigation with a larger sample size would be required to clarify the relationship between parental ratings of satisfaction and the diagnosis of their adolescent.

What domains of care are important to parents of adolescents with physical disabilities?

Parents of adolescents with physical disabilities indicated that all aspects of health care investigated were important to their satisfaction, but that certain aspects of care were more important to them than others. Parents reported that coordinated and comprehensive care for their child was most important to them, more so than any other aspect of care, including respectful and supportive care, enabling and partnership, providing specific information, and providing general information. Parents also indicated that respectful and supportive care was more important to them than the general or specific information provided to them about their child's condition, and that enabling and

partnership was more important than the general information provided. These results are also supported by parents' responses to open-ended questions about their child's care. Although not explicitly identified as important to them, parents responded about their relationship with their child's health care provider and about their reluctance to transition to adult services. Commenting about these aspects of care supports the inference that respectful and supportive care and coordinated and comprehensive care were important to parents' satisfaction with services.

Respectful and supportive care, coordinated and comprehensive care, and enabling and partnership are all components of family-centered care. Family-centered care is a method of service delivery that emphasizes partnership between providers and parents, focuses on the decision-making role of the family, and recognizes parents as experts in their child's needs (Rosenbaum et al., 1998). Communication, information gathering, mutual respect, and trust are important elements of the family-provider partnership, a component of family-centered care (Knapp et al., 2010).

Previous studies have not directly sought parents' perspectives regarding areas of care important to them, but have investigated factors associated with or predictive of their satisfaction. For example, Law et al. (2003) found that parents were most satisfied when services were delivered within a family-centered framework, suggesting that family-centered care is important to parental satisfaction with their child's health care. Similarly, Denboba et al. (2006) found that parent's sense of partnership with their child's health care provider was associated with satisfaction with services. Finally, Turchi et al. (2009) found that family-centered care was related to parent satisfaction with

their child's health care services, and that both of these factors were related to coordination of medical care.

Parents rated coordinated and comprehensive care as the most important element of their child's care. They reported that it is important that professionals working with their child consider the needs of the whole child, collaborate regarding their goals, deliver consistent information, and ensure that team members remain continuous over time. Care coordination has not directly been identified as important to parents, but it has been associated with positive family and child outcomes including higher parental satisfaction with services, increased care utilization, less family burden, fewer child school absences, and increased reports of family-provider partnership (Lawson et al., 2011; McConachie & Logan, 2003; Turchi et al., 2009). Where previous studies have suggested continuity of care has been an important factor regarding parental satisfaction, the current study provides evidence that parents consider coordinated and comprehensive care as the most important feature of their child's care.

Another component of family-centered care that parents indicated as important was a respectful and supportive parent-provider partnership. Parents reported that it was important that their child's health care provider recognize them as an individual, treat them as an equal partner in their child's care, foster a caring atmosphere, give them enough time to talk during the encounter, and help them feel competent as a parent. Having a respectful and supportive relationship with their child's health care provider was more important to parents than the amount or type of information provided to them about their child's progress and condition. Although it has not been directly identified as important to parents in previous studies, the parent-provider partnership has been

associated with increased satisfaction with care, improved access to services, decreased missed school days, fewer unmet service needs, and transition preparedness (Denboba et al., 2006; Galil et al., 2006; Knapp et al., 2010). The parent-provider relationship aspect of family-centered care has previously been associated with positive outcomes and currently has been explicitly identified by parents as important to their satisfaction with their child's health care.

The relationship between areas of care important to parents and adolescent demographic characteristics was explored and yielded mixed findings. Aspects of care parents rated as important were not related to age of their child, but were related to perceived severity of their condition. Parents of adolescents with more severe conditions reported that it was less important for them to experience enabling and partnership with the health care provider. Previous research has suggested that parents of adolescents with more functional limitations are less likely to report experiencing family-centered care (Kuo et al., 2011; Thompson et al., 2009) and family-provider partnership (Knapp et al., 2010). Although the current results suggest that parent satisfaction and adolescent condition severity are not related to each other, it is possible that parents of adolescents with more severe conditions have not experienced family-provider partnership to the same degree, and thus do not regard it as important. It is also possible that the low statistical reliability ($\alpha = .37$) of this subscale influenced this finding.

Parent ratings of importance were also associated with the diagnosis of their child. Parents of adolescents diagnosed with cerebral palsy and with spina bifida reported that aspects of family-centered care were more important to them than to parents of adolescents diagnosed with other conditions. Parents of adolescents diagnosed with

cerebral palsy and with spina bifida indicated that coordinated and comprehensive care and enabling and partnership aspects of care were more important to them than parents of adolescents diagnosed with other conditions; parents of adolescents diagnosed with cerebral palsy also showed this difference for respectful and supportive care and receiving general information about their child's condition. While Kuo et al. (2011) indicated that parents of adolescents diagnosed with conditions such as attention deficit disorder, autism, and Down syndrome were less likely to report experiencing aspects of family-centered care than parents of adolescents diagnosed with conditions such as diabetes, cerebral palsy, and muscular dystrophy, differences among parent groups with respect to what they consider important aspects of care have not been investigated. The current results indicate that areas of care important to parents are different depending on their child's diagnosis and the perceived severity of their condition.

How similar are adolescent perceptions to those of their parents?

Adolescents and parents were asked about their perceptions regarding their experiences with health care services, and this information was collected using two different measures. Therefore, the results from both of these groups could not be directly compared using traditional statistical analyses. However, because both measures assessed similar interpersonal aspects of the health care experience (e.g. communication with provider, relationship with provider, sharing information), it is possible to describe and discuss similar overall themes emerging from the adolescent and parent data.

The adolescents and parents who participated in this study indicated that they were generally very satisfied with their health care services. This finding is similar to

those of previous studies that investigated adolescent and parent perspectives separately. For example, Petersen et al. (2006) found that the majority of parents sampled were satisfied with the care their child received after traumatic brain injury, and Galil et al. (2006) found that parents of children with special health care needs reported high ratings of overall satisfaction with their child's health services. Similarly, adolescents reported moderate to high ratings of overall satisfaction with health care services (Freed et al., 1998; Litt and Cuskey, 1984) as did adolescents with chronic neurological conditions (Mah et al., 2006).

Comparing adolescent and parent responses gives further insight into their opinions about satisfaction with care. For example, Mah et al. (2006) found that although both parent and adolescent groups reported high ratings of satisfaction, parents' ratings were significantly higher than those of adolescents. Parents were more satisfied than adolescents overall with health care services, and with almost all specific aspects of care including having ongoing and open communication with clinic staff, feeling welcomed in the clinic, and having information held in a private and confidential manner (Mah et al., 2006). Similarly, Byczkowski et al. (2010) found that although there were no significant differences among parents' and adolescents' ratings of overall satisfaction with services, parents were significantly more satisfied than adolescents about specific aspects of care including being involved in making decisions about care and receiving understandable answers to questions.

The results of the current study are similar. At first glance it appears as though parents and adolescents reported similar perspectives of the health care experience because they reported similar high ratings of satisfaction with overall health care

services. However, upon closer examination of comparable aspects of care, it is evident that parents and adolescents had slightly different perspectives regarding their satisfaction with their relationship and their communication with the health care provider.

Adolescents and parents reported similar perspectives about their relationship with the health care provider according to both quantitative and qualitative measures. Both groups reported high ratings of satisfaction with the supportive and respectful relationships aspect of health care. This subscale included items such as whether the provider showed an understanding of feelings, showed they care, and provided enough time to talk and make decisions. Adolescents and parents also commented about this aspect of care as a part of the care experience that they "liked best". Both groups indicated that staff were caring, helpful, and friendly, and that they felt staff recognized them and were familiar with their case.

Parents and adolescents reported similar perspectives about their satisfaction with the relationship with health care providers, but they showed different patterns of responding to this aspect of care. Adolescents residing in Corner Brook reported that they were less satisfied with supportive and respectful relationships than adolescents residing in St. John's and rural communities; parents' responses did not show this pattern. However, parents indicated that they were most satisfied with the relationship with their child's health care provider, significantly more so than with three other domains of care investigated. Adolescents did not indicate any differences in their ratings of satisfaction with care. Therefore, while adolescents and parents agreed that they were very satisfied with their relationship with the health care provider, it is important to recognize that place of residence had an impact on adolescents' perspectives but not on parents' perspectives,

and that parents identified they were most satisfied with this area of care while adolescents did not.

Adolescents' and parents' perspectives of their relationship with health care providers are different and this finding has been supported by the previous research literature. For example, previous studies have indicated that adolescents and parents hold different views about the patient-provider relationship, especially regarding the sharing of information, privacy and confidentiality, and involvement in the decision-making process (e.g., Byczkowski et al., 2010; Mah et al., 2006; Shaw et al., 2006; Sonneveld et al., 2012). The current study describes additional features that differ between adolescents and parents with regard to patient-provider relationships; parents reported that this area of care was most satisfying to them and place of residence influenced adolescent perceptions. It is possible that different expectations about travelling to attend medical appointments and physical discomfort during travel are factors that potentially influenced adolescents' perceptions of their relationship with health care providers; these factors would not have had the same impact on parents. However, due to the paucity of research in this area, the limited sample size, and low variability of the data, these possibilities need to be investigated further in future research.

Communication and sharing of information was another area of care assessed by both adolescent and parent questionnaires; it was not referenced in response to open-ended questions about the care experience. This subscale included items such as the extent to which providers discussed details of treatment, explained medical procedures to be carried out, and provided information about progress. Again, adolescents and parents reported similar high levels of satisfaction with this area of care. While adolescents did

not show differences in their satisfaction with different areas of care, parents were significantly less satisfied with receiving information about their child's assessment results, progress, or therapy, their child's condition, or community groups than with the other family-centered areas of care investigated.

This finding is surprising given the findings of previous research. For example, adolescents in prior studies have indicated that communication with their health care provider is an important feature of their satisfaction with health care services (e.g., van Staa et al., 2011) and have identified that this is an area of care that could be improved upon (Mah et al., 2006). Parents have generally reported being very satisfied with their communication with their child's health care provider (e.g., Wood et al., 2009). When their perspectives about family-provider communication have been directly compared, adolescents have reported being less satisfied than their parents with their provider's ability to communicate and share information with them (Mah et al., 2006; Shaw et al., 2006; Sonneveld et al., 2012). It was not possible to statistically compare adolescent and parent satisfaction with provider communication in the current study. While it is important to note that both groups reported being very satisfied with the patient-provider communication they experienced, parents indicated their satisfaction could be improved upon regarding written communication of their child's care and progress. Future study directly comparing adolescent and parent perspectives could elucidate whether this result is statistically significant, whether it is due to different expectations from parents and adolescents regarding the content and format of information communicated, or whether it is due to different practices or preferences about how information is communicated to both groups.

In response to open-ended questions about their experiences, adolescents and parents made similar comments about areas of care they would like done differently. While most adolescent and parent participants reported they would not change anything, decreasing clinic wait time was addressed by respondents in both groups with similar suggestions about how to improve this undesirable aspect of their health care experience. Although structural aspects of care, such as wait times, were not being investigated in this study, it is important to note that it was referenced by both adolescents and parents, and has been indicated as an area for improvement in previous studies (e.g., Byczkowski et al., 2010).

Even though it was not possible to directly compare adolescent and parent responses regarding their satisfaction with care using traditional statistical analyses, it was possible to investigate whether adolescent and parent responses were related to each other. Correlational results indicated that adolescent and parent perspectives regarding their overall satisfaction with care were not related to each other. That is, adolescents who were highly satisfied with health care services were not more likely to have parents who were highly satisfied with services. This lack of relationship between adolescent and parent satisfaction has not been reported in the previous research reviewed. It provides further support to the tenet that adolescent and parent perspectives of satisfaction with care are distinct and should not be considered interchangeable or synonymous with each other.

Based on the cumulative results of this and prior studies, it appears as though adolescents and parents are satisfied overall with the health care services received, but the specific relative ratings of satisfaction for both groups differ. Adolescents, but not

parents, from certain geographical areas were more satisfied with the patient-provider relationship. Parents, but not adolescents, reported the most satisfaction with the parent-provider relationship and the least satisfaction with information sharing. Given these differences in the details of their responses, and that adolescent and parent responses are not related, it is important to note that parents' perspectives about the health care experience are neither accurate nor appropriate substitutes for those of adolescents. It is important to seek the opinions of adolescents themselves to evaluate the extent to which they are satisfied with their health care services.

How similar are adolescents' and parents' perceptions about what's important to them?

In addition to giving their perspectives about satisfaction with health care services, adolescents and parents reported about which aspects of care were important to them. Adolescents and parents reported that all areas of care assessed were important to their satisfaction, but that some aspects of care were more important than others. Taken separately, adolescents reported that information sharing and communication and teen centered services were more important to them than supportive and respectful relationships and supporting independence. Parents reported that comprehensive and coordinated care was more important to them than all other aspects of care assessed; they also indicated that respectful and supportive care and enabling and partnership were more important than receiving information about their child's condition.

In other words, parents and adolescents both indicated that supportive and respectful relationships with health care providers were very important to them. However, adolescents reported that this aspect of care was less important to them than

both information sharing and communication and teen centered services, while parents reported that only coordinated and comprehensive care was more important than respectful and supportive care. Furthermore, parents indicated differences in the importance of the parent-provider relationship depending on the diagnosis of their child; adolescents did not show this pattern of responding.

A respectful and supportive relationship with their health care provider has been previously identified as important to satisfaction with care from the perspectives of both adolescents and parents (e.g., Baine et al., 1995; Shaw et al., 2006). In fact, adolescents have identified that this aspect of care is more important to them than other health care processes (Shaw et al., 2006) and parents have identified that caring, respectful, individualized, and supportive relationships are very important to their satisfaction (King et al., 1997). Based on these findings, it was not surprising that adolescents and parents participating in this study reported that this aspect of care was important to them, but it was unexpected that it was not the most important aspect of care. Instead, adolescents indicated that two other areas of care were more important to them and parents indicated that coordinated and comprehensive care was more important to them. While the current and previous research studies have not directly compared perspectives from adolescents and parents regarding aspects of care important to them, the overall theme from findings suggests that a supportive and respectful relationship is important to adolescents and parents, but its relative importance to both groups differs.

Sharing information and communicating with health care providers was another area of care assessed by both adolescent and parent questionnaires, and results suggest that this aspect of the health care experience was important to both adolescents and their

parents. Although it appears that adolescents and parents reported similar perspectives regarding this domain of care, there were differences in their patterns of responding. Adolescents reported that information sharing and communication about their medical condition was one of the most important aspects of their care. Parents indicated that all other aspects of care were more important to them than receiving information about their child's condition. Although adolescents and parents both indicated that communication with their health care provider was important to them, they differed regarding the relative importance of this aspect of the health care experience.

Communication of information has previously been identified as important to adolescents and their parents. In separate studies, adolescents have identified that open and direct communication with their health care provider is important to their satisfaction (Garth & Aroni, 2003) and parents have identified that sharing information with their child's health care provider is important to them (King et al., 1997). While both groups of participants in the current study identified information sharing and communication as important, further evaluation highlighted that adolescents' and parents' perspectives differed. Adolescents indicated that this was one of the most important aspects of their care while parents indicated that it was least important to them.

Considering adolescent and parent roles during the medical encounter, their ratings of the importance of information sharing and communication make sense. As adolescents are the patients, they experience the medical condition and its associated procedures and treatments. Therefore, information about their condition, progress, and treatment would be particularly salient to them because they would be experiencing the associated potential harm and benefits. Adolescents have previously reported that they

want information about medical procedures communicated to them (Garth & Aroni, 2003) and it is reasonable that sharing this information with their health care provider would be more important to them than other aspects of care. Alternately, parents are often responsible for coordinating various medical appointments (Lawson et al., 2011) so it stands to reason that receiving information about their child's condition would be less important to them than receiving care that is coordinated and comprehensive. Although adolescents and parents have reported that all aspects of the care experience are valued, the relative importance of various aspects of care differed, potentially influenced by their different experiences during the medical appointment.

While previous research has not directly compared adolescent and parent perspectives regarding the importance of the patient-provider relationship and communication, it has identified differences between adolescent and parent perspectives regarding other aspects of care. This provides further support for the tenet that adolescents and parents hold distinct views about aspects of care important to their satisfaction. For example, in a qualitative study, Mitchell and Sloper (2001) evaluated aspects of health care that children and their parents identified as important indicators of quality services. While both groups identified staff attitudes and behaviors as important, what this meant to children and parents differed. Children discussed the importance of welcoming attitudes among staff, having opportunities to make friends, being involved in making decisions about their care, and participating in leisure activities with peers. Parents discussed the importance of having a well-trained staff, having staff listen to their ideas and wishes, understanding the medical language, having services meet their individual needs, and having collaboration among agencies. Children and parents had

different perceptions about important aspects of the health care experience (Mitchell & Sloper, 2001).

In a similar qualitative study, Mitchell and Sloper (2003) also found that children and their parents identified different aspects of care as important to them. Even though both groups identified the importance of staff being knowledgeable, having respect for them, and listening to them, children and parents identified different priorities within these themes. Children prioritized staff knowing about their condition and how to help, listening to them and asking for their ideas, and allowing them to make choices, while parents prioritized staff meeting the child's and family's needs, treating family members with respect, respecting the family's culture, and listening to both the child and family. Parents and children placed importance on similar, yet different aspects of care (Mitchell & Sloper, 2003).

Similarly, Byczkowksi et al. (2010) found slight differences among adolescent and parent responses to important aspects of the medical encounter. Overall, parents and adolescents shared perspectives about what went well during a medical encounter, but parents and adolescents did not view issues of confidentiality the same way. Adolescents felt that it was important to have confidential communication with their health care providers, while parents felt that information about their child should be shared with them (Byczkowski et al., 2010). Although it appeared that adolescents and parents had similar perspectives, there were differences in their views about what was important to their satisfaction with the health care experience.

It is evident from the current and previous findings that adolescents and their parents hold overall similar views regarding which aspects of care are important to them.

Interpersonal aspects of care including their relationship and their communication with health care providers were important to their satisfaction with the health care experience. Having trust in the health care provider, being able to ask and answer questions, and feeling respected and valued were important to both parents and adolescents. However, both groups identified that different aspects of care were important to them to different degrees. Adolescent participants in the current study were less concerned about the type of relationship they had with their health care provider and more concerned about their communication about their medical condition and treatment options. Parent participants were less concerned with receiving information about their child's condition and valued coordinated and comprehensive care more. The findings of prior research did not compare adolescent and parent views regarding the importance of the patient-provider relationship and of information sharing and communication, but did highlight other aspects of care in which both groups appeared to share opinions about medical care, but differed regarding specific values. The cumulative results of these research studies suggest that, although they may appear similar, adolescents and parents do not share opinions about specific factors important to them regarding their satisfaction with health care services. Adolescents value different aspects of care than their parents.

Do adolescent perceptions of care relate to their intentions to adhere to treatment plans?

Most adolescents reported that they received suggestions from health care providers for things to do at home as part of their treatment plan, and the majority of these adolescents reported that they intended to adhere to these treatment recommendations, even if this meant only "sometimes". Regression analysis of

adolescents' responses to this item determined that adolescents' responses regarding their intentions to follow treatment recommendations could not be reliably predicted from their reported satisfaction with health care services.

The finding that adolescent satisfaction could not predict their reported intentions to adhere to treatment recommendations differs from the findings of previous research. For example, Litt and Cuskey (1984) found that adolescent satisfaction with health care was predictive of attendance at follow-up appointments, one aspect of treatment adherence. Freed et al. (1998) expanded on this work and determined that adolescent satisfaction with care was predictive of their intentions to attend follow-up appointments, rather than their actual attendance at appointments. Brown and Wissow (2009) found that adolescents who discussed sensitive health topics with their health care provider had more positive perceptions about the encounter and were more likely to participate in and take responsibility for treatment.

Satisfaction with health care has been found to be an important determinant of intentions to adhere to treatment recommendations, but that finding was not supported by the current study. It is possible that little variability in the data limited the findings of the current study, as most adolescents reported that they were satisfied with health care services and also that they intended to adhere to treatment recommendations. A larger and more diverse sample with greater variability in intentions would clarify this finding.

The results of the current study provide evidence that the relationship between adolescent satisfaction and intentions to adhere to treatment recommendations is not linear, but may be influenced by other factors. For example, Fotheringham and Sawyer (1995) indicated that adolescent treatment adherence is complex because it is influenced

by both adolescents and parents, by developmental challenges such as rebellion against authority, and by confusion over adherence responsibility. Similarly, DiMatteo (2004) suggested that, in addition to satisfaction with care, there are several factors that are associated with adolescent treatment adherence including beliefs and attitudes about treatment, social and cultural norms, social support, and family commitment to treatment. Further research would be needed to clarify the impact of these factors on the relationship between satisfaction with care and treatment adherence among adolescents with physical disabilities.

Considerations for sources of error

There are several limitations to this study. Firstly, error may have been introduced during participant recruitment. To ensure patient confidentiality, health care center staff identified potential research participants and invited them to meet with the researcher to learn more about the study; only participants present for their health care visit were invited to participate. It is possible that differences existed between adolescents who were and were not briefed by clinic staff, who were or were not present for their clinic appointment, and who did and did not choose to meet with the researcher. Furthermore, the small sample size of this study limits the ability to generalize the results to other adolescent populations and to other health care facilities. A larger sample with fewer opportunities for selection and response bias was not logistically possible for this study, but would strengthen the findings of future research.

Secondly, neither adolescents nor their parents completed screening measures to assess their literacy levels prior to completing questionnaires. While adolescents were

screened for their ability to understand and to use a Likert rating scale, their comprehension of questionnaire items may have influenced their responses and, hence, their results. Parents did not complete screening measures to assess their ability to participate in this research. Including assessment for literacy level of all participants would resolve this potential source of error in future research.

Thirdly, adolescent and parent participants completed the questionnaires at the health center in the exam room. Questionnaires were completed prior to meeting with their health care provider in order to sample participants' overall health care experience (rather than the immediate visit) and to account for potential bias of a positive or negative experience during the current clinic visit. To account for motor and reading ability, the researcher read questionnaire items aloud to adolescent participants and circled adolescents' indicated responses. Although this removed bias potentially caused by adolescent physical limitations, it is possible that completing the questionnaires in their exam room in the presence of the researcher and their parent introduced positive response bias among adolescents' reports.

Fourthly, the presentation order of the "satisfaction" and "importance" questionnaires for parents and adolescents was counterbalanced, but the open-ended questions were asked by the researcher at the end of the session. It is possible that participants were primed in their responses to the open-ended questions, in that they focused on issues addressed in the questionnaires. Counterbalancing of survey and open-ended questions would resolve this issue in future research.

Finally, there were some concerns with the questionnaires used in this study. Because adolescents' perceptions of their health care are important, it is important to

develop valid and reliable measures to assess their satisfaction that can then be administered by health care providers. In this study, reliability analyses of the GYV-20 (Satisfaction), GYV-20 (Importance), MPOC-20 (Satisfaction), and MPOC-20 (Importance) indicated that overall reliability of the measures was high, but reliability of the measures' subscales was inconsistent. The MPOC-20 (Satisfaction) was the most well-developed and validated measure used in this study and reliability ratings were high and similar to those found during its development and use (King et al., 2004). The GYV-20 (Satisfaction) was originally adapted from the MPOC for use with adolescent populations (Gan et al., 2008) and is a validated measure also. The MPOC-20 (Importance) was adapted from the MPOC-20 (Satisfaction) and the GYV-20 (Importance) was adapted from the GYV-20 (Satisfaction) for use in this study. As such, their psychometric properties had not previously been determined and reliability results for subscales of these measures were more variable. Further analyses of these measures suggested that the adaptation to assess "importance" altered the structure of some subscales, and that the creation of new subscales would better fit the data from this participant sample. As this study was exploratory and descriptive in nature using a small sample size, the author-defined subscales of all measures were used for data analysis of this study. However, it would be prudent for future research to closely examine the reliability of these measures prior to their use.

Conclusions and future directions

Despite its limitations, the current study provides further information about the perspectives of parents and adolescents with chronic physical disabilities about their

health care experiences. Consistent with the findings of previous research, both adolescents and their parents reported high ratings of satisfaction with the interpersonal aspects of health care. Although they could not be directly compared, adolescents and parents were satisfied with their care, but there were slight differences in their patterns of responding, indicating that parents' perspectives are not appropriate proxies for those of adolescents' perspectives. Adolescents and parents may appear to share views, but adolescents have their own opinions about their health care experience, separate from those of their parents.

The current study adds to the body of research on this topic, as it investigated areas of care adolescents and their parents identify as important to their satisfaction. Previous studies have not directly sought this information, but have attempted to investigate variables related to satisfaction after the fact. Although measures to assess importance need to be further developed, the information gleaned from them here is useful to provide insight into important aspects of the patient-provider or parent-provider relationships. Any efforts needed to improve patient or parent satisfaction with care could focus on pertinent interpersonal factors identified by these populations here, to efficiently improve satisfaction with service delivery in areas identified by adolescents and parents. In other words, if adolescent satisfaction needs to be improved, it would be better to reduce wait times and improve information sharing and communication and teen centered services, rather than aspects of supporting independence or supportive relationships.

There are several opportunities for future research in this area. It would be interesting to conduct a longitudinal study to investigate whether there are changes in

satisfaction or aspects of care important to adolescents and their parents over time, especially regarding the transition to adult care (perhaps younger adolescents value friendly relationships, while older adolescents value receiving information) or whether appointment frequency or duration were related to satisfaction ratings. Furthermore, the current study investigated whether satisfaction was related to intentions to follow treatment recommendations; further longitudinal study could investigate whether satisfaction was related to actual treatment adherence, rather than intended adherence.

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Appendix A
Participant Forms
Information Letter

January 2008

Dear Participant,

I am a psychology student at Memorial University of Newfoundland currently working on my Master's thesis. My research project looks at how adolescents and their parents feel about the health care services they receive at the Rehabilitation Department of the Janeway Child Health and Rehabilitation Centre. At this time, I would like to invite you to participate in this research.

Participation in this project first involves completing a screening questionnaire and then completing three short questionnaires about the services you receive at the Janeway Rehab Centre. They will take about 15 minutes to complete.

Your choice to participate in this research is completely **voluntary** and you may choose to drop out at any time. You are free to leave out any question(s) that you do not feel comfortable answering. When you are ready to return your questionnaires, just put them into the provided envelope and return them to me.

You can be sure that all of your responses to the questionnaires are strictly confidential and anonymous. You are not asked to write your name on the questionnaires so there is no way of knowing how you responded. Only people involved with the research (my supervisor and myself) will see the completed questionnaires, assuring that your responses are absolutely confidential. Questionnaires will be stored in a secure place when this project is completed.

Your choice to take part in this study will **not affect your future medical care**. Your health care provider will not be told if you have participated in this study and will not be told how you responded to the questionnaires. Your future health care will not be affected by whether or not you participate.

The proposal for this research has been approved by the Human Investigations Committee (HIC). If you have any ethical concerns about the research that have not been dealt with, you may contact the Chairperson of HIC at hic@mun.ca or at (709) 777-6974.

This research has the potential to influence the way in which health care services are delivered to adolescent patients. However, **it is not known whether this study will benefit you**. It is not expected that participating in this research will be harmful in any way. But, if you find you begin to feel concerned or anxious you can contact patient counseling at the Janeway Family Center at Southcott Hall. Or, you can talk to Janine Hubbard, Registered Psychologist at the Development and Rehabilitation Centre, at 777-4814. If you have any other questions or concerns, feel free to contact me or my supervisor.

Thank you very much for your time.

Sincerely,

Sarah Hollett, B.Sc.; M.Sc. candidate
Memorial University of Newfoundland
sarah_t_hollett@hotmail.com

Dr. Christine Arlett, Ph.D.; R.Psych.
Memorial University of Newfoundland
carlett@play.psych.mun.ca

Consent Form – Signatures

Study Title: Perceptions of Quality of Medical Care: Perspectives from Adolescents and their Parents.

Investigators: Sarah Hollett, B.Sc.; M.Sc. candidate
Christine Arlett, Ph.D., R.Psych.

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

To be filled out and signed by the participant:

Please check as appropriate:

I have read the information letter . Yes { } No { }
I have had the opportunity to ask questions and discuss this study. Yes { } No { }
I have received satisfactory answers to all of my questions. Yes { } No { }
I have received enough information about the study. Yes { } No { }
I have spoken to Sarah Hollett and she has answered my questions Yes { } No { }
I understand that I am free to withdraw from the study

- at any time
- without having to give a reason
- without affecting my future health care Yes { } No { }

I understand that it is my choice to be in the study
and that I may not benefit. Yes { } No { }

I agree to take part in this study. Yes { } No { }

_____ _____
Signature of participant Date

_____ _____
Signature of witness Date

<u>Assent of minor participant (if appropriate):</u>

_____ _____
Signature of minor participant Date

_____ _____
Relationship to participant named above Age

Researcher Signature

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

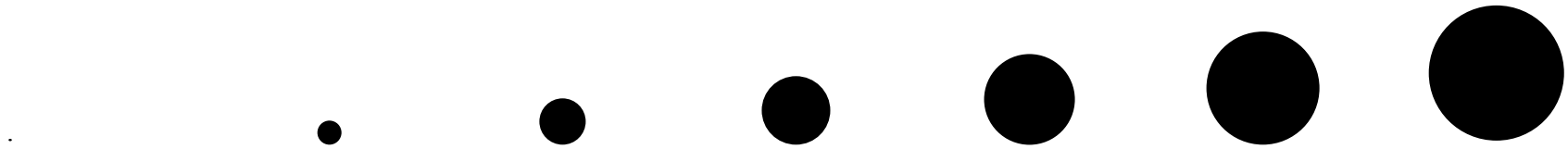
_____ _____

Signature of investigator Date

Telephone number: _____

What is something you really like to do?_____
Circle the number that matches how much you like to do this?

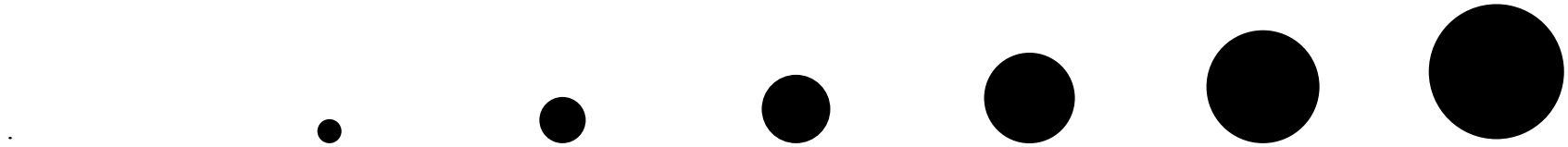
1 2 3 4 5 6 7



Never Sometimes A lot

What is something you really hate to do?_____
Circle the number that matches how much you like to do this?

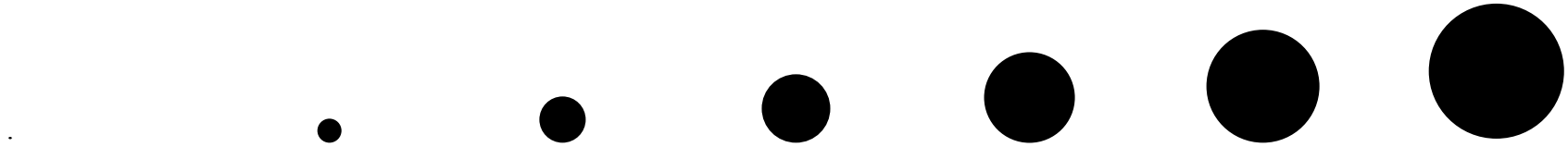
1 2 3 4 5 6 7



Never Sometimes A lot

What is something you like to do sometimes and don't like to do sometimes?_____
Circle the number that matches how much you like to do this?

1 2 3 4 5 6 7



Never Sometimes A lot

More About You

1. How old are you? _____

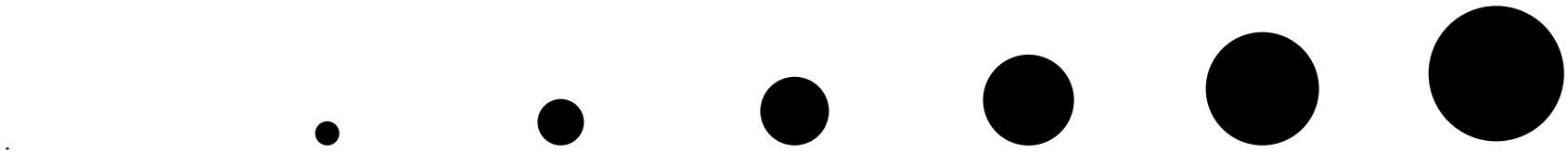
2. Are you male or female? _____Male _____Female

3. Where do you live (St John's, CBS, etc.)? _____

4. What type of diagnosis do you have? _____

5. How severe would you say that your disability is?

1 2 3 4 5 6 7



Very Minor Very Serious

6. Do you use any of these devices to help you get around?
   _____Power Wheelchair _____Crutches, canes, or a walker
   _____Manual Wheelchair _____Walk independently without assistance

7. Do staff give you suggestions for things to do at home (e.g. stretching, exercises)?
   _____Yes _____No

8. Do you follow these instructions?
   _____Yes _____Sometimes _____No

9. What do you like the best about what the staff do at the Janeway?

10. What is something you would like to see done differently by staff at the Janeway?

Giving Youth a Voice Questionnaire (GYV-20) Satisfaction

Caron Gan, R.N., M.Sc.N.; Kent Campbell, Ph.D.; Andrea Snider, Ph.D., C.Psych.; Janine Hubbard, M.A.
Bloorview MacMillan Children's Centre

We would like to understand and measure the experiences of youth who have a physical disability. In particular, we wish to know about your perceptions of the care you have been receiving over the past year from your **Treatment (Rehabilitation) Centre**.

The questions in this section are based on youth, like yourself, have told us about the way care is sometimes offered. We would like you to indicate how much the event or situation happens (or doesn't happen) to you at your treatment centre. You are asked to answer each question on a scale from 7 (A Lot) to 1 (Never).

The following is an example of the kinds of questions you will be asked.
This example also shows what your answer could mean.

*How much do the **people** who give you questionnaires...*	A lot			Sometimes			Never	Not Applicable
... provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (A lot), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If you circled #0 (Does not apply to me), it means that you have never received a questionnaire and so you cannot answer the question. I

Please think about your experiences over the past year at the Janeway.

For each question, please indicate how much the event or situation happens to you by circling **one** number (from 1 to 7) that you feel best fits your experience at the Janeway.

PEOPLE refer to those individuals who work directly with you. These **may include** teachers, psychologists, therapists, social workers, doctors etc.

Indicate how much the event or situation happens to you.

How much *do the people who work with you...*	A lot			Sometimes			Never	Does not apply to me
1. ... give you enough time when you need to make choices in treatment?	7	6	5	4	3	2	1	0
2. ... make sure you have a chance to say what is important to you?	7	6	5	4	3	2	1	0
3. ... help you feel more sure of yourself?	7	6	5	4	3	2	1	0
4. ... tell you details about your treatment, such as the reasons for it, what is being done, and for how long?	7	6	5	4	3	2	1	0
5. ... talk to you honestly?	7	6	5	4	3	2	1	0
6. ... treat you as a young adult rather than a child?	7	6	5	4	3	2	1	0
7. ... trust that you know yourself best?	7	6	5	4	3	2	1	0
8. ... recognize that you and your family have the final say when making decisions about your treatment or services?	7	6	5	4	3	2	1	0
9. ... show an understanding of your feelings?	7	6	5	4	3	2	1	0
10. ... show they care about you?	7	6	5	4	3	2	1	0

Indicate how much the event or situation happens to you.

How much *do the people who work with you...*	A lot			Sometimes			Never	Does not apply to me
11. ... inform you of how treatments might harm you or help you?	7	6	5	4	3	2	1	0
12. ... look at all of your needs (e.g. cognitive, emotional, and social needs), as well as your physical needs?	7	6	5	4	3	2	1	0
13. ... treat you as an individual rather than like all other youth with a disability?	7	6	5	4	3	2	1	0
14. ... answer your questions?	7	6	5	4	3	2	1	0
15. ... seem aware that your needs change as you get older?	7	6	5	4	3	2	1	0
16. ... get along well with youth?	7	6	5	4	3	2	1	0
17. ... give you a chance to say what you want to get out of treatment?	7	6	5	4	3	2	1	0
18. ... explain what they are doing?	7	6	5	4	3	2	1	0
19. ... make you feel that you can trust them?	7	6	5	4	3	2	1	0
20. ... offer you useful information about how you are doing?	7	6	5	4	3	2	1	0

Giving Youth a Voice Questionnaire (GYV-20) Importance

Caron Gan, R.N., M.Sc.N.; Kent Campbell, Ph.D.; Andrea Snider, Ph.D., C.Psych.; Janine Hubbard, M.A.
Bloorview MacMillan Children's Centre

We would like to understand and measure the experiences of youth who have a physical disability. In particular, we wish to know about your perceptions of the care you have been receiving over the past year from your **Treatment (Rehabilitation) Centre**.

The questions in this section are based on youth, like yourself, have told us about the way care is sometimes offered. We would like you to indicate how important it is that the event or situation happens (or doesn't happen) to you at your treatment centre. You are asked to answer each question on a scale from 7 (Very important) to 1 (Not important).

The following is an example of the kinds of questions you will be asked.
This example also shows what your answer could mean.

***How important** is it that the people who give you questionnaires...*	Very important			Somewhat important			Not important	Not Applicable
... provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (Very important), it means that it is important that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Somewhat important), it means that it is somewhat important that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Not important), it means that although you have received questionnaires, it is not important that the instructions are clear.

If you circled #0 (Does not apply to me), it means that you have never received a questionnaire and so you cannot answer the question. I

Please think about your experiences over the past year at the Janeway.

For each question, please indicate how important it is that the event or situation happens to you by circling **one** number (from 1 to 7) that you feel best fits your experience

PEOPLE refer to those individuals who work directly with you. These **may include** teachers, psychologists, therapists, social workers, doctors etc.

Indicate how important it is that the event or situation happens to you.

How important *is it that the people who work with you...*	Very important			Somewhat important			Not important	Does not apply to me
1. ... give you enough time when you need to make choices in treatment?	7	6	5	4	3	2	1	0
2. ... make sure you have a chance to say what is important to you?	7	6	5	4	3	2	1	0
3. ... help you feel more sure of yourself?	7	6	5	4	3	2	1	0
4. ... tell you details about your treatment, such as the reasons for it, what is being done, and for how long?	7	6	5	4	3	2	1	0
5. ... talk to you honestly?	7	6	5	4	3	2	1	0
6. ... treat you as a young adult rather than a child?	7	6	5	4	3	2	1	0
7. ... trust that you know yourself best?	7	6	5	4	3	2	1	0
8. ... recognize that you and your family have the final say when making decisions about your treatment or services?	7	6	5	4	3	2	1	0
9. ... show an understanding of your feelings?	7	6	5	4	3	2	1	0
10. ... show they care about you?	7	6	5	4	3	2	1	0

Indicate <u>how important</u> it is that the event or situation happens to you.

How important *is it that the people who work with you...*	Very important			Somewhat important			Not important	Does not apply to me
11. ... inform you of how treatments might harm you or help you?	7	6	5	4	3	2	1	0
12. ... look at all of your needs (e.g. cognitive, emotional, and social needs), as well as your physical needs?	7	6	5	4	3	2	1	0
13. ... treat you as an individual rather than like all other youth with a disability?	7	6	5	4	3	2	1	0
14. ... answer your questions?	7	6	5	4	3	2	1	0
15. ... seem aware that your needs change as you get older?	7	6	5	4	3	2	1	0
16. ... get along well with youth?	7	6	5	4	3	2	1	0
17. ... give you a chance to say what you want to get out of treatment?	7	6	5	4	3	2	1	0
18. ... explain what they are doing?	7	6	5	4	3	2	1	0
19. ... make you feel that you can trust them?	7	6	5	4	3	2	1	0
20. ... offer you useful information about how you are doing?	7	6	5	4	3	2	1	0

Measure of Processes of Care (Satisfaction)

Please circle the number that corresponds with the extent to which you **agree** with the following statements.

1=Never 4=Sometimes 7=To a great extent

To what extent do the people who work with your child:

1. Help you feel competent as a parent?

   1 2 3 4 5 6 7

2. Provide you with written information about what your child is doing in therapy?

   1 2 3 4 5 6 7

3. Provide a caring atmosphere rather than just give you information?

   1 2 3 4 5 6 7

4. Let you choose when to receive information and the type of information you want?

   1 2 3 4 5 6 7

5. Look at the needs of your "whole" child (e.g. mental, emotional, and social needs) instead of just at physical needs?

   1 2 3 4 5 6 7

6. Make sure that at least one team member is someone who works with you and your family over a long period of time?

   1 2 3 4 5 6 7

7. Fully explain treatment choices to you?

   1 2 3 4 5 6 7

8. Provide opportunities for you to make decisions about treatment?

   1 2 3 4 5 6 7

9. Provide enough time for you to talk so you don't feel rushed?

   1 2 3 4 5 6 7

10. Plan together so they are all working in the same direction?

    1 2 3 4 5 6 7

11. Treat you as an equal rather than just as the parent of a patient (by not referring to you as “Mom” or “Dad”)?

1 2 3 4 5 6 7

12. Give you information about your child that is consistent from person to person?

1 2 3 4 5 6 7

13. Treat you as an individual rather than as a “typical” parent of a child with a disability?

1 2 3 4 5 6 7

14. Provide you with written information about your child’s progress?

1 2 3 4 5 6 7

15. Tell you about the results from assessments?

1 2 3 4 5 6 7

16. Give you information about the types of services offered at the organization or in your community?

1 2 3 4 5 6 7

17. Have information available about your child’s disability (e.g. its cause, how it progresses, future outlook)?

1 2 3 4 5 6 7

18. Provide opportunities for the entire family to obtain information?

1 2 3 4 5 6 7

19. Have information available to you in various forms, such as a booklet, kit, video, etc.?

1 2 3 4 5 6 7

20. Provide advice on how to get information or to contact other parents (e.g. organization’s parent resource library)?

1 2 3 4 5 6 7

1=Never **4=Sometimes** **7=To a great extent**

Measure of Processes of Care (Importance)

Please circle the number that corresponds with the **importance** of the following statements.

1=Not important 4=Somewhat important 7=Very important

How <u>important</u> is it to you that the people who work with your child:

1. Help you feel competent as a parent?

   1 2 3 4 5 6 7

2. Provide you with written information about what your child is doing in therapy?

   1 2 3 4 5 6 7

3. Provide a caring atmosphere rather than just give you information?

   1 2 3 4 5 6 7

4. Let you choose when to receive information and the type of information you want?

   1 2 3 4 5 6 7

5. Look at the needs of your "whole" child (e.g. mental, emotional, and social needs) instead of just at physical needs?

   1 2 3 4 5 6 7

6. Make sure that at least one team member is someone who works with you and your family over a long period of time?

   1 2 3 4 5 6 7

7. Fully explain treatment choices to you?

   1 2 3 4 5 6 7

8. Provide opportunities for you to make decisions about treatment?

   1 2 3 4 5 6 7

9. Provide enough time for you to talk so you don't feel rushed?

   1 2 3 4 5 6 7

10. Plan together so they are all working in the same direction?

    1 2 3 4 5 6 7

11. Treat you as an equal rather than just as the parent of a patient (by not referring to you as “Mom” or “Dad”)?

1 2 3 4 5 6 7

12. Give you information about your child that is consistent from person to person?

1 2 3 4 5 6 7

13. Treat you as an individual rather than as a “typical” parent of a child with a disability?

1 2 3 4 5 6 7

14. Provide you with written information about your child’s progress?

1 2 3 4 5 6 7

15. Tell you about the results from assessments?

1 2 3 4 5 6 7

16. Give you information about the types of services offered at the organization or in your community?

1 2 3 4 5 6 7

17. Have information available about your child’s disability (e.g. its cause, how it progresses, future outlook)?

1 2 3 4 5 6 7

18. Provide opportunities for the entire family to obtain information?

1 2 3 4 5 6 7

19. Have information available to you in various forms, such as a booklet, kit, video, etc.?

1 2 3 4 5 6 7

20. Provide advice on how to get information or to contact other parents (e.g. organization’s parent resource library)?

1 2 3 4 5 6 7

1=Not important **4=Somewhat important** **7=Very important**

Appendix B

Number of Participants Responding to Items of Measures, Missing Responses, Item Means, and Standard Deviations

Table B1

Number of Participants Responding to Items of the Giving Youth a Voice 20 (Satisfaction)

	Satisfaction score										
Item	1	2	3	4	5	6	6.5	7	Missing	Mean	SD
1					2	7		12		6.48	0.68
2					1	6	1	13		6.60	0.58
3					2	3		15	1	6.65	0.67
4			1		1	5		13	1	6.45	1.00
5						4	1	16		6.79	0.41
6			1			5		15		6.57	0.93
7					3	6		12		6.43	0.75
8					2	4		14	1	6.60	0.68
9					3	2		16		6.62	0.74
10					1	4		16		6.71	0.56
11					3	4		13	1	6.50	0.76
12					2	8		11		6.43	0.68
13					1	7		13		6.57	0.60
14					2	3		16		6.67	0.66
15			1		1	7		12		6.38	0.97
16					1	2		18		6.81	0.51
17			1		1	3		15	1	6.55	1.00
18					1	3		17		6.76	0.54
19					1	2		18		6.81	0.51
20					2	4		15		6.62	0.67

Table B2

Number of Participants Responding to Items of the Giving Youth a Voice 20 (Importance)

	Importance score									
Item	1	2	3	4	5	6	7	Missing	Mean	SD
1	1			2		7	11		6.10	1.48
2					2	2	17		6.71	0.64
3					4	7	10		6.29	0.78
4					1	1	19		6.86	0.48
5						2	19		6.90	0.30
6						3	18		6.86	0.36
7				1	2	4	14		6.48	0.87
8						2	19		6.90	0.30
9					1	2	18		6.81	0.51
10						4	17		6.81	0.40
11					1	3	17		6.76	0.54
12					1	6	14		6.62	0.59
13					2	2	17		6.71	0.64
14					2	3	16		6.67	0.66
15					1	4	16		6.71	0.56
16						6	15		6.71	0.46
17					3	4	14		6.52	0.75
18					1		19	1	6.90	0.45
19						2	19		6.90	0.30
20					1	4	16		6.71	0.56

Table B3

Number of Participants Responding to Items of the Measure of Processes of Care 20 (Satisfaction)

	Satisfaction score									
Item	1	2	3	4	5	6	7	Missing	Mean	SD
1				1	2	2	16		6.57	0.87
2		1			5	6	8	1	5.95	1.23
3					3	2	16		6.62	0.74
4			1		2	9	9		6.19	0.98
5			1			2	18		6.71	0.90
6				2	1	3	15		6.48	0.98
7		1			1	3	16		6.52	1.17
8			1		1	6	13		6.43	0.98
9			1			2	18		6.71	0.90
10			2			5	14		6.38	1.20
11					2	4	14	1	6.60	0.68
12				1	1	4	14	1	6.55	0.83
13				1		3	16	1	6.70	0.73
14				2	3	6	8	2	6.05	1.03
15				1	1	5	12	2	6.47	0.84
16		2	1		2	4	11	1	5.90	1.68
17			2	1	1	1	15	1	6.30	1.38
18			1	1		5	13	1	6.40	1.10
19		1	1	2	3	3	10	1	5.80	1.54
20		2			5	4	9	1	5.80	1.54

Table B4

Number of Participants Responding to Items of the Measure of Processes of Care 20 (Importance)

	Importance score									
Item	1	2	3	4	5	6	7	Missing	Mean	SD
1						4	17		6.81	0.40
2				1	3	6	11		6.29	0.90
3					1	5	15		6.67	0.58
4					5	5	11		6.29	0.85
5						2	19		6.90	0.30
6						2	19		6.90	0.30
7						1	19	1	6.95	0.22
8						2	18	1	6.90	0.31
9				1		1	19		6.81	0.68
10						1	20		6.95	0.22
11				1		6	13	1	6.55	0.76
12						6	14	1	6.70	0.47
13						3	16	2	6.84	0.37
14					4	3	13	1	6.45	0.83
15					2	1	17	1	6.75	0.64
16					3	5	12	1	6.45	0.76
17				1	2	1	16	1	6.60	0.88
18					3	4	13	1	6.50	0.76
19				2	3	2	13	1	6.30	1.08
20			1	1	5	3	10	1	6.00	1.21

Appendix C

Analysis of Variance Summary Tables

Table C1

Analysis of Variance (Within Subjects) for Subscales of the GYV-20 (Satisfaction)

Source	*df*	*F*	*p*
Subscales	3	0.86	0.47
Error	60		

Table C2

Analysis of Variance (Between Subjects) for the GYV-20 (Satisfaction) Subscales and Gender

Source	*df*	*F*	*p*
Gender	1	0.60	0.45
Error	19		

Table C3

Analysis of Variance (Between Subjects) for the GYV-20 (Satisfaction) Subscales and Diagnosis

Source	*df*	*F*	*p*
Diagnosis	2	0.82	0.46
Error	18		

Table C4

Analysis of Variance for the GYV-20 (Satisfaction) Subscales and Place of Residence

Source	*df*	*F*	*p*
Between subjects			
Place of Residence	2	3.17	0.07
Within-group Error	18		
Within subjects			
Subscales	3	3.64	0.02
Subscales x Place of Residence	6	2.74	0.02
Within-group Error	54		

Table C5

Analysis of Variance (Within Subjects) for the GYV-20 (Importance) Subscales

Source	*df*	*F*	*p*
Subscales	3	5.73	0.00
Error	60		

Table C6

Analysis of Variance (Between Subjects) for the GYV-20 (Importance) Subscales and Gender

Source	*df*	*F*	*p*
Gender	1	0.10	0.76
Error	19		

Table C7

A*nalysis of Variance (Between Subjects) for the GYV-20 (Importance) Subscales and Diagnosis*

Source	*df*	*F*	*p*
Diagnosis	2	0.61	0.56
Error	18		

Table C8

Analysis of Variance (Between Subjects) for the GYV-20 (Importance) Subscales and Place of Residence

Source	*df*	*F*	*p*
Place of Residence	2	0.02	0.98
Error	18		

Table C9

Analysis of Variance (Within Subjects) for the MPOC-20 (Satisfaction) Subscales

Source	*df*	*F*	*p*
Subscales	4	6.56	0.00
Error	76		

Table C10

Analysis of Variance (Between Subjects) for the MPOC-20 (Satisfaction) Subscales and Adolescent Gender

Source	*df*	*F*	*p*
Gender	1	1.86	0.19
Error	18		

Table C11

Analysis of Variance for the MPOC-20 (Satisfaction) Subscales and Adolescent Diagnosis

Source	*df*	*F*	*p*
Between subjects			
Diagnosis	2	3.93	0.04
Error	17		
Within subjects			
Subscales	4	7.54	0.00
Subscales x Diagnosis	8	1.58	0.15
Error	68		

Table C12

Analysis of Variance (Between Subjects) for the MPOC-20 (Satisfaction) Subscales and Place of Residence

Source	*df*	*F*	*p*
Place of Residence	2	2.13	0.15
Error	17		

Table C13

Analysis of Variance (Within Subjects) for the MPOC-20 (Importance) Subscales

Source	*df*	*F*	*p*
Subscales	4	5.99	0.00
Error	76		

Table C14

Analysis of Variance (Between Subjects) for the MPOC-20 (Importance) Subscales and Adolescent Gender

Source	*df*	*F*	*p*
Gender	1	1.35	0.26
Error	18		

Table C15

Analysis of Variance for the MPOC-20 (Importance) Subscales and Adolescent Diagnosis

Source	*df*	*F*	*p*
	Between subjects		
Diagnosis	2	3.79	0.04
Error	17		
	Within subjects		
Subscales	4	7.27	0.00
Subscales x Diagnosis	8	1.55	0.16
Error	68		

Table C16

Analysis of Variance (Between Subjects) for the MPOC-20 (Importance) Subscales and Place of Residence

Source	*df*	*F*	*p*
Place of Residence	2	0.62	0.55
Error	17		

Appendix D

Exploratory Reliability Analyses of Questionnaire Subscales

Table D1

Reliability analysis of the MPOC-20 (Importance)

Subscale	Item Numbers Included	Cronbach's Alpha	Remove Item	Adjusted Cronbach's Alpha
Respectful and Supportive Care	1, 3, 9, 11, 13	.54	9	.56
Providing General Information	16, 17, 18, 19, 20	.85		
Providing Specific Information	2, 14, 15	.57	2	.75
Coordinated and Comprehensive Care	5, 6, 10, 12	.55	10	.60
Enabling and Partnership	4, 7, 8	.37	7	.32

Table D2

Reliability analysis of the GYV-20 (Satisfaction)

Subscale	Item Numbers Included	Cronbach's Alpha	Remove Item	Adjusted Cronbach's Alpha
Supportive and Respectful Relationships	1, 9, 10, 12, 20	.88		
Information Sharing and Communication	4, 5, 11, 14, 18	.57	4	.67
Supporting Independence	2, 3, 7, 8, 17	.66	17	.77
Teen Centered Services	6, 13, 15, 16, 19	.64	15	.77

Table D3

Reliability analysis of the GYV-20 (Importance)

Subscale	Item Numbers Included	Cronbach's Alpha	Remove Item	Adjusted Cronbach's Alpha
Supportive and Respectful Relationships	1, 9, 10, 12, 20	.67	20	.72
Information Sharing and Communication	4, 5, 11, 14, 18	.77		
Supporting Independence	2, 3, 7, 8, 17	.82		
Teen Centered Services	6, 13, 15, 16, 19	.56	6	.59

Appendix E

Correlation Matrices for Measure Subscales

Table E1

Item correlations and p-values for MPOC-20 (Importance) Subscale –Respectful and Supportive Care

Item Number	1	3	9	11	13
1	--------	--------	--------	--------	--------
3	.14 (0.54)	-------	-------	-------	--------
9	-.14 (0.55)	-.04 (0.86)	-------	-------	--------
11	.03 (0.89)	.22 (0.36)	-.08 (0.74)	-------	--------
13	.48 (0.04)	.22 (0.36)	-.10 (0.68)	.69 (0.00)	--------

Table E2

Item correlations and p-values for MPOC-20 (Importance) Subscale – Providing General Information

Item Number	16	17	18	19	20
16	--------	--------	--------	--------	--------
17	.44 (0.05)	-------	-------	-------	--------
18	.77 (0.00)	.71 (0.00)	-------	-------	--------
19	.40 (0.08)	.41 (0.07)	.64 (0.00)	-------	--------
20	.57 (0.01)	.49 (0.03)	.51 (0.02)	.60 (0.01)	--------

Table E3

Item correlations and p-values for MPOC-20 (Importance) Subscale – Providing Specific Information

Item Number	2	14	15
2	--------	--------	--------
14	.40 (0.08)	-------	--------
15	-.07 (0.78)	.62 (0.00)	--------

Table E4

Item correlations and p-values for MPOC-20 (Importance) Subscale – Coordinated and Comprehensive Care

Item Number	5	6	10	12
5	--------	--------	--------	--------
6	.45 (0.04)	-------	-------	--------
10	-.07 (0.76)	-.07 (-0.76)	-------	--------
12	.51 (0.02)	.15 (0.54)	.35 (0.13)	--------

Table E5

Item correlations and p-values for MPOC-20 (Importance) Subscale – Enabling and Partnership

Item Number	4	7	8
4	--------	--------	--------
7	.35 (0.14)	-------	--------
8	.30 (0.20)	-.08 (0.75)	--------

Table E6

Item correlations and p-values for GYV-20 (Satisfaction) Subscale – Supportive and Respectful Relationships

Item Number	1	9	10	12	20
1	--------	--------	--------	--------	--------
9	.58 (0.01)	-------	-------	-------	--------
10	.51 (0.02)	.81 (0.00)	-------	-------	--------
12	.40 (0.07)	.54 (0.01)	.60 (0.00)	-------	--------
20	.53 (0.01)	.80 (0.00)	.76 (0.00)	.49 (0.02)	--------

Table E7

Item correlations and p-values for GYV-20 (Satisfaction) Subscale – Information Sharing and Communication

Item Number	4	5	11	14	18
4	--------	--------	--------	--------	--------
5	.11 (0.97)	-------	-------	-------	--------
11	.24 (0.30)	.60 (0.01)	-------	-------	--------
14	.22 (0.36)	.56 (0.01)	.44 (0.05)	-------	--------
18	.05 (0.83)	.56 (0.01)	.28 (0.23)	.47 (0.03)	--------

Table E8

Item correlations and p-values for GYV-20 (Satisfaction) Subscale – Supporting Independence

Item Number	2	3	7	8	17
2	--------	--------	--------	--------	--------
3	.46 (0.04)	-------	-------	-------	--------
7	.65 (0.00)	.40 (0.08)	-------	-------	--------
8	.47 (0.04)	.48 (0.03)	.67 (0.00)	-------	--------
17	.28 (0.23)	.18 (0.45)	.12 (0.63)	.16 (0.50)	--------

Table E9

Item correlations and p-values for GYV-20 (Satisfaction) Subscale – Teen Centered Services

Item Number	6	13	15	16	19
6	--------	--------	--------	--------	--------
13	.37 (0.10)	-------	-------	-------	--------
15	.08 (0.73)	.04 (0.87)	-------	-------	--------
16	.35 (0.12)	.54 (0.01)	.05 (0.82)	-------	--------
19	.77 (0.00)	.37 (0.10)	.25 (0.27)	.62 (0.00)	--------

Table E10

Item correlations and p-values for GYV-20 (Importance) Subscale – Supportive and Respectful Relationships

Item Number	1	9	10	12	20
1	--------	--------	--------	--------	--------
9	.62 (0.00)	-------	-------	-------	--------
10	.62 (0.00)	.79 (0.00)	-------	-------	--------
12	.50 (0.02)	.58 (0.01)	.52 (0.02)	-------	--------
20	.03 (0.88)	.15 (0.52)	-.03 (0.90)	.26 (0.26)	--------

Table E11

Item correlations and p-values for GYV-20 (Importance) Subscale – Information Sharing and Communication

Item Number	4	5	11	14	18
4	--------	--------	--------	--------	--------
5	.25 (0.28)	-------	-------	-------	--------
11	.25 (0.28)	.78 (0.00)	-------	-------	--------
14	.64 (0.00)	.34 (0.14)	.19 (0.42)	-------	--------
18	.41 (0.07)	1.00 (0.00)	.81 (0.00)	.25 (0.29)	--------

Table E12

Item correlations and p-values for GYV-20 (Importance) Subscale – Supporting Independence

Item Number	2	3	7	8	17
2	--------	--------	--------	--------	--------
3	.47 (0.03)	-------	-------	-------	--------
7	.70 (0.00)	.52 (0.02)	-------	-------	--------
8	.37 (0.10)	.33 (0.14)	.18 (0.43)	-------	--------
17	.74 (0.00)	.33 (0.15)	.75 (0.00)	.45 (0.04)	--------

Table E13

Item correlations and p-values for GYV-20 (Importance) Subscale – Teen Centered Services

Item Number	6	13	15	16	19
6	--------	--------	--------	--------	--------
13	.25 (0.28)	-------	-------	-------	--------
15	-.21 (0.35)	.32 (0.16)	-------	-------	--------
16	.34 (0.13)	.22 (0.35)	.25 (0.28)	-------	--------
19	-.13 (0.57)	.37 (0.10)	.42 (0.06)	.15 (0.51)	--------

Appendix F

Factor Analysis

Table F1

Factor analysis for MPOC-20 (Importance)

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1		0.57			
2			-0.63		
3			-0.47		
4				0.51	
5	0.57				
6				-0.53	
7					
8			0.48		
9		-0.80			
10		-0.80			
11					0.74
12	0.66				
13					0.67
14			-0.50		
15				0.44	
16	0.80				
17	0.78				
18	0.88				
19	0.79				
20	0.75				

Table F2

Factor analysis for the GYV-20 (Satisfaction)

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1			0.61		
2	0.75				
3					-0.61
4		0.80			
5				0.47	
6			0.47		
7					0.60
8	0.76				
9	0.84				
10	0.74				
11	0.79				
12	0.80				
13			0.59		
14				-0.63	
15		0.77			
16				-0.46	
17		0.83			
18					-0.54
19				-0.50	
20	0.72				

Table F3

Factor analysis for the GYV-20 (Importance)

Item	Factor 1	Factor 2	Factor 3
1	0.66		
2	0.88		
3	0.61		
4			0.79
5		-0.47	
6		0.83	
7	0.74		
8		-0.47	
9	0.88		
10	0.67		
11		-0.47	
12	0.83		
13	0.72		
14			0.64
15	0.63		
16	0.63		
17	075		
18		-0.47	
19			0.59
20	0.47		

Appendix G

Adolescent and Parent Responses Regarding What They Like Best and What They Would Like to Change About Health Services

Participant	Adolescent		Parent	
	Like Best	Different	Like Best	Different
101		Nothing	In tune with what's going on; provide new opportunities and experiences; take part themselves (PT and RT); friendly	Nursing personnel – more of a primary nurse; liaison person in the know about things instead of always someone different
102			Make you feel like family; personal connection; recreation room; entertaining, good staff; don't know what to do without them; good to talk to; upbeat	Getting info to trickle down through more efficiently; paper trail; shortness of staff
104	Help people; friendly	Nothing	Very friendly; helpful	No problems personally

105			Way they treat him (son); don't consider that he has a disability	No
106	Really nice; treat you like a person; make sure you have a normal life; like vacation – swimming pool, play room	No, not really	All nice; known for a long time	No
107	Help get better; make life easier; really nice	Nothing		

108	Like everyone's personality; easy to get along with; tell the truth about treatments; give enough notice about treatments	Nothing	Know them on a personal level; general interest in personal life, genuine concern; never make you feel uncomfortable, treat as a real person; good information – booklet/binder; clinic approach – all under one roof, good team approach	Nothing – good changes have been made re: staff; costs of things/orthotic aids/equipment; don't know can purchase themselves; ask for prescription and go – price differences across provinces; wiser with experiences
109	Does everything right/good; need any help, they're there	No, doing really good		

110	Everything – too much, everything great	No	Atmosphere and communication; never left out of the loop; needed them, they're there; know family situation; medical and rehab all together; everybody knows you	Stay here all the time; transition to adult not looking forward to it, same personal care won't be there
111	Give time to make own decisions; friendly	No	Easy to work with; explain everything	No
112		No	Follow-up; explain progress; show x-rays; feel involved; consider the patient	No
113	Kind; nice people; help out a lot	No; really, really good	Really good; really help; do what they can for her (daughter)	No; care is the best she (daughter) could have gotten

114	Everyone knows me, I know them; I could write a book! Seem friendly and caring; treat me the same as they would treat anyone else	Shorter wait times	Compassionate; always wonderful; same as 'adolescent'	Wait times; appointment never on time; don't understand that parents have to work, can't miss ½ day of work
115	Help with problems; anything wrong they let you know and what they can do to help	No		No
116	Really friendly	No	One-on-one; listen to me; know 'adolescent' better than anyone	No, been great

117	Friendly	Same as parent	Friendly; talk to you if need it; sit and talk on a bad day; always been there since "adolescent" was a baby	More activities for when kids are in play room; more things to get involved in while waiting; no problems
118	Agree with "parent"	Faster wait times	Friendly; helpful; nice people	No
119	There when you need something, you can just call	When person in waiting, aware that others can hear talk about other (patients); more confidentiality in common area		
120			Very comfortable to come in; recognize; familiarity	Lines move faster; waiting time decreased

121	Make you feel welcome; answer questions honestly	No	Honest; keep up to date on progress; call them anytime with problems	No
122	Treat you like you're not a kid; relate and talk to you	No	Make you feel comfortable; everything treated as important	No problems; very helpful
123	Saved me; I wouldn't be here if not for them	No, not really	Come over and try to help as much as they can; supportive; good ideas/advice	No, not really